

# ILLINOIS PANDAS/PANS ADVISORY COUNCIL



**2018 Report**

**December 4, 2018**

## TABLE OF CONTENTS

ILLINOIS PANDAS/PANS ADVISORY COUNCIL .....	3
MEMBERSHIP .....	3
UNDERSTANDING PANDAS/PANS .....	4
Epidemiology/Demographics .....	5
Clinical Presentation.....	5
Etiology and Disease Mechanisms for PANDAS (Post-streptococcal symptoms) .....	6
PANDAS/PANS BURDEN IN ILLINOIS .....	7
STANDARD DIAGNOSTIC AND TREATMENT GUIDELINES .....	8
Absolute Criteria .....	8
Major Criteria .....	8
Minor Criteria Group 1 .....	8
Minor Criteria Group 2 .....	8
Diagnostic Formulas.....	8
Additional Supporting Evidence .....	9
Clinical Management.....	9
CURRENT RESEARCH .....	11
INCREASING CLINICAL AWARENESS .....	14
NETWORK OF EXPERTS .....	16
OUTREACH .....	16
RECOMMENDATIONS FOR THE FUTURE .....	17
ENACT STANDARD PRACTICE GUIDELINES .....	17
DEVELOP MECHANISMS TO INCREASE PUBLIC AWARENESS .....	17
PROVIDE OUTREACH TO EDUCATORS AND PARENTS .....	17
INCREASE UNDERSTANDING OF THE BURDEN ON ILLINOIS.....	18
CITATIONS.....	19

## ILLINOIS PANDAS/PANS ADVISORY COUNCIL

### MEMBERSHIP

- Dr. Anette Mhabhi, DO, Synergy Health Care, Chairwoman
- Nick Florian, Legislative Liaison, Illinois Department of Public Health
- Allison Nickrent, Legislative Liaison, Illinois Department of Public Health
- Gloria E. Barrera, MSN, RN, PEL-CSN, Illinois State Board of Education
- Illinois State Representative Peter Breen
- Dr. Pamela Campbell, MD, Division Chief Child Psychiatry, Southern Illinois University, Carbondale, IL
- Illinois State Senator Michael Connelly
- Illinois State Representative Deb Conroy
- Illinois State Senator Tom Cullerton
- Dr. Caoimhe Dardis, PhD, PANDAS/PANS Parent, Naperville, IL
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- Dr. Miroslav Kovacevic, MD, Pediatrician, Hinsdale, IL
- Wendy Nawara, MSW, Executive Director, PANDAS/PANS Advocacy and Support, Naperville, IL
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- Dr. Greg Sharon, MD, Immunologist, Asthma and Allergy Center, Bloomingdale, IL
- Tiffany Tumminaro, LCSW, CADC, Life Care Counseling, Glen Ellyn, IL
- Dr. Anjum Usman-Singh, MD, True Health Medical Center, Naperville, IL

The Illinois PANDAS/PANS Advisory Council was created in 2015 in accordance with *Public Act 99-0320* to:

- Make recommendations concerning standard practice guidelines for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections/ Pediatric Acute-onset Neuropsychiatric Syndrome (PANDAS/PANS)
- Develop mechanisms to increase clinical awareness of PANDAS/PANS
- Provide outreach to educators and parents
- Develop a network of volunteer experts on PANDAS/PANS to serve as resources within the State.

The Illinois Department of Public Health (IDPH) has managed oversight and support of the council since 2015. Council priorities in 2018 included continued review of the standards of care that medical providers in the state can access, and education about PANDAS/PANS for citizens, health providers, mental health providers, medical students, and education professionals.

The council consists of physicians, who are board certified in immunology, pediatrics, psychiatry, osteopathy, and family medicine and have expertise and experience in the diagnostics and treatments of PANDAS/PANS and/or Autism Spectrum Disorders; other health and mental health care professionals with expertise and experience in the diagnostics and treatments of PANDAS/PANS; certified members of the School Health and Special Education Divisions of the State Board of Education; representatives of organizations or groups that advocate on behalf of children and families suffering from PANDAS/PANS and/or Autism Spectrum Disorders; a principal investigator from the National Institute of Mental Health; legislators; and parents of children who have been diagnosed with PANDAS/PANS.

## UNDERSTANDING PANDAS/PANS

For nearly thirty years, PANDAS has been studied extensively at the National Institute of Mental Health (NIMH) and elsewhere across the U.S. and internationally.<sup>3</sup> More recently, a consortium of clinicians, researchers, and scientists has dedicated considerable time and effort to clinical care and study of children with PANDAS and the larger cohort of patients with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).<sup>2</sup> A medically treatable cause can be found for most cases of PANDAS and PANS. Preliminary data suggest that with appropriate treatment early in the course of illness, and effective use of antibiotics prophylaxis, we may be able to prevent up to 25-30 percent of childhood mental illnesses.<sup>4</sup>

Evidence shows that Group A streptococcal infections (GAS) are the causal factor in PANDAS. Antibody studies demonstrate that children with PANDAS have antibodies that invoke bioactivity to produce the acute symptomatology.<sup>5-8</sup> Animal studies show the transference of antibodies from an originally infected mouse to a naïve, healthy mouse produce the same behavioral abnormalities and OCD symptoms.<sup>9-10</sup> This demonstrates that PANDAS/PANS is an immune mediated antibody process. Placebo-controlled trials of antibiotic therapies demonstrate significant benefits for both PANDAS and PANS, and trials of prophylactic antibiotics have shown that preventing strep infections leads to reduction or cessation of the neuropsychiatric exacerbations.<sup>11</sup> In mild cases with positive strep cultures, a single course of antibiotics given to eradicate the strep infection can be effective in eliminating the psychiatric and behavioral symptoms. Additionally, a growing body of evidence indicates that PANDAS/PANS are autoimmune encephalitic disorders.<sup>12-13</sup> There are two different types of autoimmune encephalopathies that produced a response to infection with Group A Strep bacteria. One is Sydenham Chorea, which is the neurologic manifestation of acute rheumatic fever, while the other is PANDAS.<sup>22</sup> Because intravenous immunoglobulin (IVIG) is widely accepted as a standard treatment for post-infectious autoimmune encephalopathy,<sup>39</sup> when faced with the more moderate to severe presentations of PANDAS/PANS, physicians must rely on immunomodulatory measures, including steroids, intravenous immunoglobulin, and therapeutic plasmapheresis (TPA) to halt this neuroinflammatory process.

### PANDAS

Pediatric  
Autoimmune  
Neuropsychiatric  
Disorders  
Associated with  
Streptococcal infections<sup>1</sup>

### PANS

Pediatric  
Acute-onset  
Neuropsychiatric  
Syndrome<sup>2</sup>

Children with PANDAS/PANS who do not receive appropriate treatment remain chronically ill and the progression of the disease may exacerbate symptomatology to the extent that they are unable to attend school, participate in the community, and in some cases may require residential care. In the most severe cases, lack of appropriate medical interventions can result in the progression of clinically associated symptoms, which may result in death due to suicide or complications due to anorexia.

## Epidemiology/Demographics

- Peak age at onset = 6.5 years<sup>2</sup>
- Boys outnumber girls approximately 2:1<sup>2</sup>
- 1 in 250 children have impairing symptoms (estimates from clinic populations<sup>2,14</sup>)
- 5 - 10% of grade-school aged children have observable GAS-related neurologic and behavioral symptoms<sup>14</sup>

## Clinical Presentation

PANDAS/PANS are defined by an unusually abrupt onset of obsessive-compulsive disorder (OCD) or eating restrictions/anorexia.<sup>1-2</sup>

Comorbidity is present in all children, with most having symptoms in at least four categories<sup>1-2,15</sup>

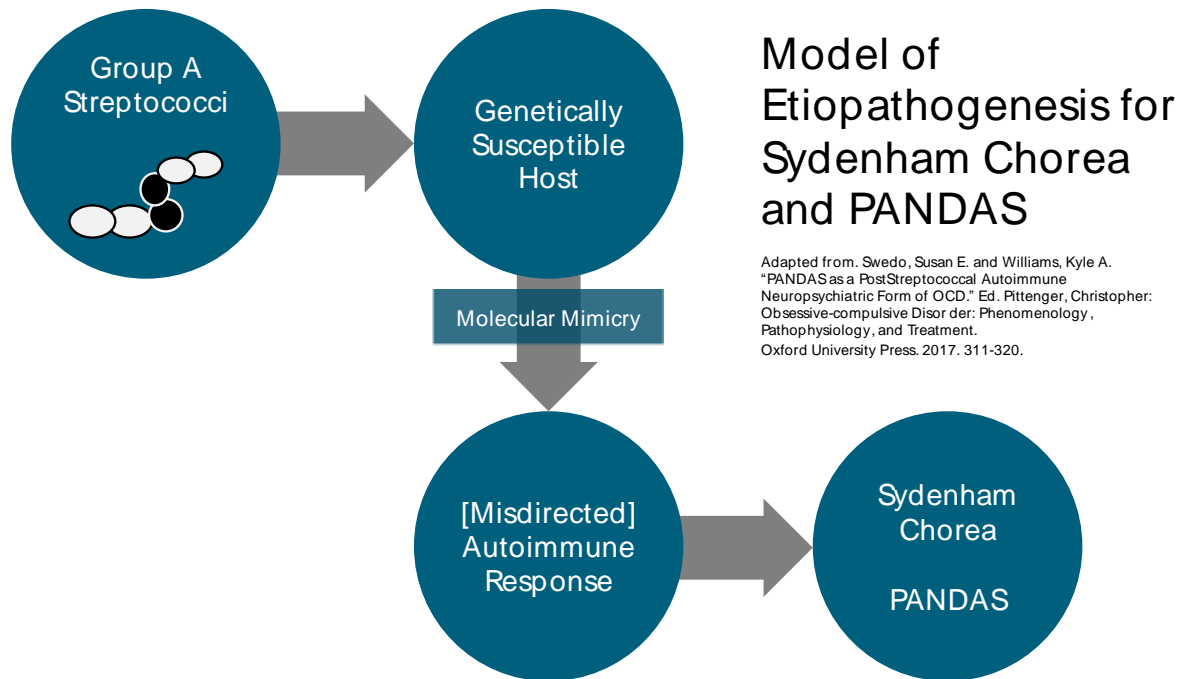
- Anxiety (particularly separation anxiety)
- Emotional lability and/or depression
- Irritability, aggression, and/or severely oppositional behaviors
- Behavioral (developmental) regression
- Deterioration of school performance
- Sensory or motor abnormalities
- Somatic signs and symptoms, including sleep disturbances, enuresis and urinary frequency

The course of illness for PANDAS/PANS is relapsing/remitting, with exacerbations preceded by infections (particularly Group A strep) and psychosocial stressors.

Although early recognition and treatment can eradicate symptoms, children who fail to receive appropriate diagnosis and treatment have increasingly severe episodes, with resultant distress and loss of function (unable to participate in extracurricular activities; stop seeing friends; unable to attend school or even leave a “safe” room in their house). Severe cases often require prolonged psychiatric hospitalizations and may end in death (suicide, starvation/dehydration, or accidents caused by impulsive behaviors).

## Etiology and Disease Mechanisms for PANDAS (Post-streptococcal symptoms)

It is understood that 65-100percent of patients with Sydenham Chorea have obsessive-compulsive symptoms, with that rate increasing with recurrences.<sup>20</sup> Obsessive-compulsive disorder (OCD) symptoms are often more persistent and difficult to treat than the chorea.<sup>21</sup>



Group A streptococci (GAS) are “molecular mimics” that cause the immune system to produce antibodies which misrecognize host antigens as foreign. This temporary loss of tolerance may become permanent if the blood-brain barrier is breached (which GAS exotoxins can do) or if the immune system is repeatedly activated.<sup>22</sup>

Evidence for an etiologic role of GAS infections in PANDAS comes from:

- Clinical observations showing 1:1 correlation between (occult) GAS infections and neuropsychiatric symptom exacerbations<sup>1,15</sup>
- Epidemiologic studies demonstrating association between GAS infections and choreiform movements, tics, and problem behaviors<sup>14,23</sup>
- Treatment of GAS infections improves OCD/tic symptoms<sup>11,16</sup>
- Prevention of GAS infections reduces number and severity of neuropsychiatric symptom exacerbations<sup>24,25</sup>
- Cross-reactive antibodies present during acute illness, but not during convalescence<sup>26,27</sup>
- Animal models show that repeated GAS infections in lymphoid tissues, such as tonsils and adenoids, stimulate T-cell production and immune activation in Central Nervous System<sup>10</sup>

Evidence for immune dysfunction in PANDAS comes from:

- Efficacy of immunomodulatory therapies, such as IVIG and plasmapheresis<sup>17-19</sup>
- Cross-reactive antibodies produce cell signaling, as evidenced by activation of CaM KII<sup>28,27</sup>
- Animal models have demonstrated that PANDAS sera/antibodies produce neuropsychiatric symptoms, even by passive transfer<sup>10,28-30</sup>

## PANDAS/PANS BURDEN IN ILLINOIS

The true incidence of PANDAS/PANS is currently unknown. Members of the PANDAS/PANS Collaborative Consortium estimate PANDAS/PANS to affect 1-2 percent of the pediatric population<sup>31</sup>, while the PANDAS Network reports the incidence at 1 in 200 children<sup>32</sup>. This is not a small number of children who may be affected by PANDAS/PANS. We must do better in recognizing and treating this condition.

The CDC reports that 1 in 7 U.S. children between the ages of 2 and 8 years have a mental, behavioral, or developmental disorder. When these issues persist into adulthood, especially as a result of misdiagnosis or inadequate care, the risk of poor school outcomes, decreased employment, additional health concerns, early mortality, and the great cost of caring for people with the disorders is heightened.<sup>33</sup>

In accordance with the Illinois Mental Health 2013-2018 Strategic Plan, children suffering from PANDAS/PANS meet the definition of having a serious emotional disturbance, which is defined as the “unique needs of children and adolescents under age 18 who have, in the past year, been diagnosed with a mental, emotional, or behavioral disorder resulting in functional impairment that substantially interferes with or limits the child’s role or functioning in family, school, or community activities.”<sup>34</sup>

Hospitalizations due to PANDAS/PANS are significantly more expensive for the Illinois health care system than community-based services. Becker’s Hospital Review lists Illinois hospitals’ average daily rate for a nonprofit hospital at \$2,049.<sup>35</sup> Inpatient psychiatric care runs between \$1,200 and \$2,500 throughout the state.

A 2016 collaborative study from the PANDAS Network, the University of Buffalo, and the University of South Florida revealed that prompt diagnosis and expeditious treatment of this condition can alleviate symptoms in the short term, but can also alter the course of the disease in the long term. “While it is appreciated by a small percentage of clinicians that timely antibiotic intervention and eradication of the inciting infection are integral in the treatment of PANS, this study, for the first time, highlights the importance of such treatment in the long-term clinical picture of PANS. Although PANS is typically recurrent with some chronic features, the data reported herein suggest that early and aggressive treatment of infection may decrease both the likelihood of residual symptoms and the likelihood of recurrence, potentially preventing the high levels of functional impairment seen particularly in the postpubertal years. Having increased vigilance for new infections and exposure to GAS is likely also helpful to minimize the impact of recurrence of PANS symptoms.”<sup>40</sup>

Without appropriate diagnosis and treatment, the illness has the potential to become a chronic life-long condition, requiring extensive care. There can be no doubt that mental, behavioral, and developmental disorders, such as PANDAS/PANS, and the associated conditions of Attention Deficit Hyperactivity Disorder, OCD, Autism Spectrum Disorders, and Tourette syndrome have a substantial impact on health care, families, and communities of Illinois.

As already mentioned, NIMH has estimated 25-30 percent of childhood mental illness may be preventable through appropriate treatment of PANDAS/PANS.<sup>4</sup> If we compute this estimation with the data suggested by the Illinois Mental Health Strategic Plan, in 2012 approximately 43,750-52,500 children and adolescents may have decreased quality of life due to a missed diagnosis of PANDAS/PANS and/or misdiagnosis of serious emotional disturbance. If appropriately diagnosed and treated immediately, we could reduce this estimated number, and substantially limit the burden on the state of Illinois.

## STANDARD DIAGNOSTIC AND TREATMENT GUIDELINES

The development of the PANS/PANDAS standard diagnostic and treatment guidelines began in 2013 when a group of noted physicians met at the National Institutes of Health to discuss the significant needs of this population of sick children. A diagnostic consensus was developed and subsequently published in the *Journal of Child and Adolescent Psychopharmacology* in 2015.<sup>41</sup> Follow-up treatment guidelines were published in the same journal in July of 2017.<sup>37</sup>

The PANDAS/PANS diagnosis is based on subjective criteria and is considered a clinical diagnosis. However, as research has improved, absolute, major, and minor criteria have been developed and can be met in various combinations.<sup>36</sup>

### Absolute Criteria

- Sudden Onset. Sudden and precipitous development of symptoms over the course of hours or even a few days.
- Characteristic dynamic evolution of nature of symptoms and intensity of symptoms over a period of 2-6 weeks.

### Major Criteria

- Presence of OCD symptoms
- Separation anxiety (one or both)
  1. Daytime and nighttime dependency on parent’s physical presence
  2. Psychological dependence on familiar physical environment with or without need for parents’ presence
- Anorexia (one or more)
  1. Acute onset of food and/or liquid refusal
  2. Fear of choking
  3. Fear of vomiting
  4. Inability to swallow because of intolerable smell or texture
  5. Distorted body image (usually in children over 12, and can result from the other types of anorexia).

### Minor Criteria Group 1

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> Sleeping disorders (insomnia, night terrors, refusal to sleep alone)</li> <li><input type="checkbox"/> Behavior regression (baby talk, temper tantrums, behaviors unbecoming of actual chronological age)</li> <li><input type="checkbox"/> Emotional Lability/Depression</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Hyperactivity, inattentiveness, inability to concentrate (ADHD/ADD diagnosis compatible)</li> <li><input type="checkbox"/> Learning disability (particularly mathematics) that was not there prior to symptom onset</li> <li><input type="checkbox"/> Hallucinations</li> </ul> |
|--|---|

### Minor Criteria Group 2

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> “Hyperalert” appearance and/or “puppet-like” facial mannerisms</li> <li><input type="checkbox"/> Hypotonia</li> <li><input type="checkbox"/> Mydriasis (especially during acute phase of symptoms)</li> <li><input type="checkbox"/> Urinary frequency and/or enuresis and/or daytime incontinence</li> <li><input type="checkbox"/> Short-term memory loss</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Increased sensory responses (smells, sounds, light, touch)</li> <li><input type="checkbox"/> Fine motor skills deterioration</li> <li><input type="checkbox"/> Dysgraphia</li> <li><input type="checkbox"/> Tics and/or adventitious movements</li> </ul> |
|--|---|

### Diagnostic Formulas

<p>In patients with the acute onset of symptoms, patients must meet the <b>Absolute Criteria</b> and <b>TWO Major Criteria</b>.</p>	<p>If the acute onset is difficult to elucidate, patients must meet <b>TWO Major Criteria</b> and <b>THREE Minor Criteria</b>.</p>
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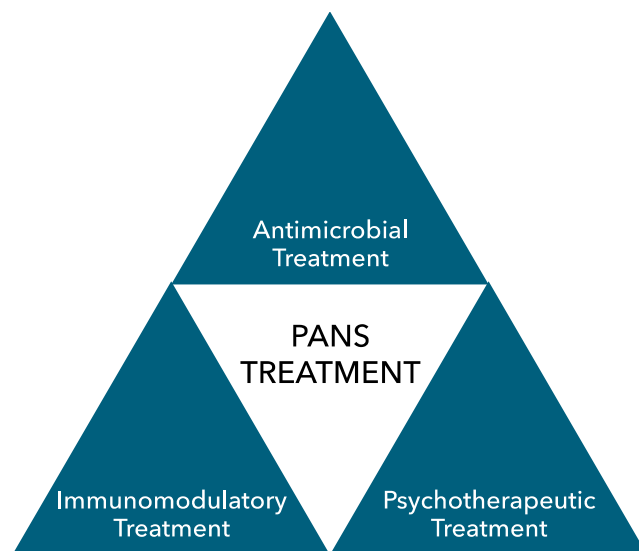


## Additional Supporting Evidence

- Positive GAS titers
- Positive EBV IgM (VCA) (EBNA)
- Positive ANA titer (speckled)
- Elevated IgE levels
- Leukopenia
- Increased Circulating Immune Complexes (c1q, c3d, Raji cells)
- Sleep study abnormalities
- MRI abnormalities
- EEG abnormalities
- PET scan abnormalities
- Positive response to antibiotic trial
- Positive response to steroid “burst”
- Other positive specific autoimmune encephalopathic antibodies such as HSV, VZV, EV, HHV-6, AntiNMDAR, ALE, GAD-65
- Cunningham Panel (Moleculera Labs)
- “The best test is still taking a thorough history and listening to the parents.” - Dr. Sue Swedo, Chief of Developmental Pediatrics, Neuroscience Branch, NIMH<sup>42</sup>

## Clinical Management

In 2014, more than 40 physicians and researchers representing the fields of immunology, infectious disease, microbiology, neuroimmunology, neurology, pediatrics, psychiatry, and rheumatology from 23 academic institutions across the U.S., Canada, and Australia convened to craft standard of care “best practice” guidelines. These evidence based, peer-reviewed guidelines, published in the Journal of Child and Adolescent Psychopharmacology July/Aug 2017<sup>37</sup>, show that there are three recommended complementary treatment modalities when treating cases of PANDAS/PANS:

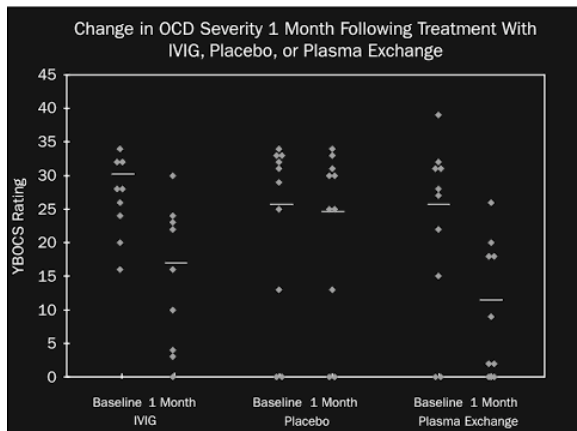


Removing the **SOURCE** of the inflammation with antimicrobial interventions.

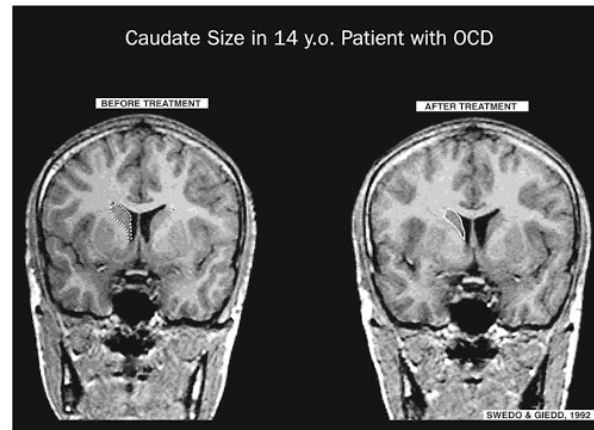
Treating disturbances of the immune **SYSTEM** with immunomodulatory and/or anti-inflammatory therapies.

Treating the **SYMPTOMS** with psychoactive medications, psychotherapies (particularly cognitive behavioral therapy), and supportive interventions.<sup>37</sup>

Early recognition and prompt treatment of occult GAS infections can produce complete symptom remission.<sup>16</sup> Antibiotics may help PANS patients, even in the absence of documented GAS infection.<sup>6</sup> Immunomodulatory therapies, such as steroids, IVIG, or therapeutic plasmapheresis are helpful for severe, debilitating symptoms.<sup>17-19</sup>



A. IVIG vs. Placebo vs. Plasmapheresis  
Improvements: 45%, 0% and 58% respectively



B. 20% reduction in caudate size following immunomodulatory treatment

**Effects of therapeutic plasmapheresis and intravenous immunoglobulin (IVIG) in PANDAS.** A. IVIG and plasmapheresis produced a significant improvement in OCD severity in children with PANDAS, relative to sham IVIG infusion (from Perlmutter et al., 1999). B. Caudate size was reduced by 20 percent in a child with PANDAS after immunomodulatory treatment (from Giedd et al., 1996).

Additionally, the PANDAS Physicians Network has developed a diagnostic flowchart for physicians to aid in recognition and treatment (<https://www.pandasppn.org/flowchart>). This chart is updated frequently to reflect the most up to date knowledge on the condition. Physicians and mental health providers are encouraged to check the site regularly.<sup>38</sup>

Quite often, children with PANDAS/PANS are also identified as having co-occurring conditions including, but not limited to, autism spectrum disorders, immune deficiencies, or other autoimmune illnesses or encephalopathies. In these cases, as in all cases of potential neuroimmune illness, it is very important that treatment decisions are made to ensure the best possible clinical outcome. For example, if a child has both a moderate to severe PANDAS, and a documented immune deficiency warranting immunomodulatory treatment, a “loading dose” of immunoglobulin may be required to halt the autoimmune attack before proceeding with the more typical monthly doses prescribed for the immune deficiency.

It is the recommendation of this council that the diagnostic criteria, practice parameters, and treatment protocols identified here shall continue to be practiced as the standard of care for PANDAS/PANS in Illinois. However, it is imperative that more physicians, educators, and mental health providers become aware of the condition and how to treat it.

## CURRENT RESEARCH

*Evidence for autoimmune encephalitis in Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS).*

Swedo S. Pediatrics & Developmental Neuroscience Branch, NIMH-Intramural, Bethesda, MD, United States. Work was supported by the intramural research program of the National Institute of Mental Health, Bethesda MD under protocols 11-M-0058 and 13-M-0028.

*Update on the use of immunoglobulin in human disease: A review of evidence*

Perez, Elena E. et al. Journal of Allergy and Clinical Immunology , Volume 139 , Issue 3 , S1 - S46

*Pediatric Inflammatory Brain Disease.*

Tran, Paula & Frankovich, Jennifer & Van Mater, Heather & C. Dale, Russell & Or-Geva, Noga & McHugh, Anne & Thienemann, Margo. (2018). 169-188. 10.1016/B978-0-323-51147-6.00014-4.

*“Chapter 17 Autoimmune Encephalitis: Overview of Clinical Recognition, Autoantibody Diagnostic Markers, and Treatment of Autoimmune Encephalitis.”*

Dale, Russell C. *Acute Encephalopathy and Encephalitis in Infancy and Its Related Disorders*, by Hideo Yamanouchi, Elsevier, 2018, pp. 123-132.

*Paediatric Autoimmune Neuropsychiatric Disorder Associated with Group A Beta-Haemolytic Streptococcal Infection: An Indication for Tonsillectomy? A Review of the Literature.*

Rajgor AD, Hakim NA, Ali S, Darr A. Int J Otolaryngol. 2018 Feb 21;2018:2681304. doi: 10.1155/2018/2681304. eCollection 2018. Review.

*Cross-Sectional Evaluation of Plasma Vitamin D Levels in a Large Cohort of Italian Patients with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections.*

Stagi S, Lepri G, Rigante D, Matucci Cerinic M, Falcini F. J Child Adolesc Psychopharmacol. 2018 Mar;28(2):124-129. doi: 10.1089/cap.2016.0159. Epub 2017 Nov 7.

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Frick LR, Rapanelli M, Jindachomthong K, Grant P, Leckman JF, Swedo S, Williams K, Pittenger C. Brain Behav Immun. 2018 Mar;69:304-311. doi: 10.1016/j.bbi.2017.12.004. Epub 2017 Dec 9.

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Sigra S, Hesselmark E, Bejerot S. Neurosci Biobehav Rev. 2018 Mar;86:51-65. doi: 10.1016/j.neubiorev.2018.01.001. Epub 2018 Jan 6. Review.

*Principles and approaches to the treatment of immune-mediated movement disorders.*

Mohammad SS, Dale RC. Eur J Paediatr Neurol. 2018 Mar;22(2):292-300. doi: 10.1016/j.ejpn.2017.11.010. Epub 2017 Dec 19. Review.

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Calaprice D, Tona J, Murphy TK. J Child Adolesc Psychopharmacol. 2018 Mar;28(2):92-103. doi: 10.1089/cap.2017.0101. Epub 2017 Aug 23.

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Zibordi F, Zorzi G, Carecchio M, Nardocci N. Eur J Paediatr Neurol. 2018 Mar;22(2):316-320. doi: 10.1016/j.ejpn.2018.01.011. Review.

*Gut Microbiota Profiling and Gut-Brain Crosstalk in Children Affected by Pediatric Acute-Onset Neuropsychiatric Syndrome and Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections.*

Quagliariello A, Del Chierico F, Russo A, Reddel S, Conte G, Lopetuso LR, Ianiro G, Dallapiccola B, Cardona F, Gasbarrini A, Putignani L. *Front Microbiol.* 2018 Apr 6;9:675. doi: 10.3389/fmicb.2018.00675. eCollection 2018.

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Marazziti D, Mucci F, Fontenelle LF. *Psychoneuroendocrinology.* 2018 Jul;93:39-44. doi: 10.1016/j.psychneuen.2018.04.013. Epub 2018 Apr 13. Review.

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*Altered cerebral glucose metabolism normalized in a patient with a pediatric autoimmune neuropsychiatric disorder after streptococcal infection (PANDAS)-like condition following treatment with plasmapheresis: a case report.*

Nave AH, Harmel P, Buchert R, Harms L. *BMC Neurol.* 2018 May 2;18(1):60. doi: 10.1186/s12883-018-1063-y.

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Burchi E, Pallanti S. *Prim Care Companion CNS Disord.* 2018 May 3;20(3). pii: 17r02232. doi: 10.4088/PCC.17r02232. Review.

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Barzman DH, Jackson H, Singh U, Griffey M, Sorter M, Bernstein JA. *Case Rep Psychiatry.* 2018 Jun 28;2018:8189067. doi: 10.1155/2018/8189067. eCollection 2018.

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Santoro JD, Frankovich J, Bhargava S. *J Clin Sleep Med.* 2018 Jul 15;14(7):1187-1192. doi: 10.5664/jcsm.7222.

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Aguilera-Albesa S, Crespo-Eguílaz N, Del Pozo JL, Villoslada P, Sánchez-Carpintero R. *J Atten Disord.* 2018 Jul;22(9):864-871. doi: 10.1177/1087054715580841. Epub 2015 Apr 16.

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Lamothe H, Baleyte JM, Smith P, Pelissolo A, Mallet L. *Brain Sci.* 2018 Aug 9;8(8). pii: E149. doi: 10.3390/brainsci8080149. Review.

*Allergic Diseases and Immune-Mediated Food Disorders in Pediatric Acute-Onset Neuropsychiatric Syndrome.*

Rosa JS, Hernandez JD, Sherr JA, Smith BM, Brown KD, Farhadian B, Mahony T, McGhee SA, Lewis DB, Thienemann M, Frankovich JD. *Pediatr Allergy Immunol Pulmonol.* 2018 Sep 1;31(3):158-165. doi: 10.1089/ped.2018.0888. Epub 2018 Sep 17.

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## INCREASING CLINICAL AWARENESS

- The Illinois Department of Public Health (IDPH) has created a PANDAS/PANS tab on its website to enable users of its site to learn more about PANDAS/PANS. The tab also provides direct links to the PANDAS Physicians Network flowchart to aid in ease of recognizing the disorder, and includes resources for physicians and families.
- A PANDAS/PANS Summit occurred on October 4, 2018. The goals of the Summit were to encourage necessary collaboration between the council/IDPH, the Illinois Department of Human Services (DHS), and the community; gather information on issues pertaining to educating medical providers, medical students, and the general public on the prompt diagnosis and treatment of PANDAS/PANS; ensure health and maximum outreach; and promote education related to the nature and extent, underlying causes, and prevention of PANDAS/PANS. Three presentations were given to physicians, mental health providers, educational providers and advocates, and parents. They can be viewed at these links:
  - <https://youtu.be/CqjTlyW-xYg> PANDAS/PANS: Moving Past Controversy to Recognition and Diagnosis - Susan E Swedo, Section of Behavioral Pediatrics, NIMH
  - <https://youtu.be/TYNei0IAV2s> Understanding the Cunningham Panel - Dr Craig Shimasaki, President and CEO Moleculera Labs
  - <https://youtu.be/5GTzwoQtgK0> PANDAS/PANS Standards of Care Summit: The Role of the School Nurse - Jessica Gerdes, School Health ISBE and Teresa Schindler, School Nurse SASSED
- The development of presentations that would provide professional education credit for participants has been investigated. These presentations would be available to members of the council to give upon request. A presentation for schools and teachers was developed and presented in Naperville and Aurora School Districts in the Fall of 2018.
- Charlie's Law, *PA100-0024*, was signed into effect on July 18, 2017. This law should have enabled children in Illinois to access insurance covered care for treatment of PANDAS/PANS. Because families continue to be met with roadblocks from insurers regarding this law, members of the council supported efforts of legislators to introduce a subsequent clarifying bill that would make it easier for families and physicians to gain access to treatments covered by insurance. The bill, HB1277, passed unanimously through the House of Representatives in November 2017, but was stalled in the Senate.
- In collaboration with the Department of Insurance, a document to answer frequently asked questions pertaining to Charlie's Law was developed and is available on the Department of Insurance website. Illinois families need a better understanding of how to navigate the insurance process.
- The council encouraged appropriate and consistent access to care for families in need of treatment. The council suggested the use of state and national experts when conducting peer-to-peer reviews as other specialists may not yet have sufficient knowledge or experience to offer an informed opinion on physician recommended care.

- Members of the council and the PANDAS/PANS Advocacy and Support organization continue to exhibit at both the Illinois Chapter of the American Academy of Pediatrics and the National American Academy of Pediatrics (AAP) conferences.
- The World Health Organization announced on June 18, 2018 its preparations for the ICD-11 (International Classifications of Diseases) diagnostic code to be implemented in 2021. Having a code for PANDAS would allow better access to insurance-covered care for all families in the state of Illinois as it describes PANDAS as an Autoimmune Encephalopathy. The diagnostic code is 8E4A.0
- Dr. Pam Campbell of the council facilitated the invitation of Dr. Susan Swedo, Chief of Developmental Neuroscience Branch of the National Institute of Mental Health, to the Southern Illinois University Medical School's Psychiatry and Pediatrics Departments in October 2018.

## NETWORK OF EXPERTS

Throughout the country there are many physicians practicing in the relevant clinical areas pertaining to the diagnostics and treatment of PANDAS/PANS. In addition, there are scientists continually researching the condition to improve upon the care of children. The PANDAS/PANS Collaborative Consortium members are listed here:

- Harvard (MGH) - Kyle Williams & Dan Geller (Child Psych), Mark Pasternack (Peds ID)
- Yale - James Leckman, Robert King (both Child Psych)
- Columbia - Dritan Agalliu (Basic Science of blood-brain barrier), Tyler Cutforth (Basic Science), Wendy Vargas (Neurology), & Shannon Delaney (Child Psychiatry, Lyme)
- Nemours/Delaware Children's Hospital - Jo Elia (Child Psych), Harry Chugani (PET neuroimaging)
- NIMH - Susan Swedo (Pediatrics), Rebecca Hommer & Paul Grant (Child Psych)
- Georgetown - Beth Latimer (Pediatric Neuro), Earl Harley (ENT) & Heidi Appel (Pediatrics)
- UNC - Jim Crowley (Genetics)
- Univ South Florida - Tanya Murphy (Child Psych), Jolan Walter (Immunology)
- Loyola University (Hinsdale, IL) - Miro Kovacevic (Pediatrics)
- University of Minnesota - Pat Cleary (basic science, microbiology of Group A strep)
- Baylor University - Eyal Muscal (Peds Rheumatology)
- Univ. Oklahoma - Madeleine Cunningham (GAS microbiology; immune response to infection)
- University of Arizona - Sydney Rice (Dev/Behav Peds), Michael Daines (Peds Immunology), Chris Speakerman (Nurse Practitioner)
- Stanford - Jenny Frankovich (Peds Rheumatology), Margo Thienemann (Child Psych)
- Moleculera Labs - Craig Shimasaki (Antibody Testing)
- PANDAS Physicians Network - David Brick (Pediatric Cardiology)
- University of California San Diego - Jay Giedd (Pediatrics)
- University of Minnesota - Gail Bernstein (Psychiatry)
- Virginia Commonwealth University/ MCV - Wei Zhao (Immunology) & David Jaffe (Neurology)
- Miami Children's Hospital - Reuven Bromberg (Rheumatology) & Ann Hyslop (Neurology)

Within the state of Illinois, the practicing members of this council can be consulted for their expertise in the appropriate areas.

- Gloria Barrera, MSN, RN, PEL-CSN, RN Course Facilitator, Illinois State Board of Education
- Teresa Schindler, RN, PEL-CSN
- Dr. Pamela Campbell, MD, Child Psychiatry, Southern Illinois University
- Dr. Anette M Nabhi, DO, Synergy Healthcare
- Wendy Nawara, MSW, Executive Director, PANDAS/PANS Advocacy and Support
- Dr. Greg Sharon, MD, Immunologist, Asthma and Allergy Center
- Tiffany Tumminaro, LCSW, CADC, Life Care Counseling
- Dr. Anjum Usman-Singh, MD, True Health Medical Center

## OUTREACH

- The professional members of the council are available as a Speakers' Bureau.
- The council has developed a list of medical associations, education associations, and medical schools throughout Illinois that can be targeted to receive general information on the diagnosis and treatments of PANDAS/PANS.
- The council has exhibited locally at the Illinois Chapter of the American Academy of Pediatrics conferences.



## RECOMMENDATIONS FOR THE FUTURE

In keeping with the original goals of *Public Act 99-0320*, while also expanding upon our goals for 2019, the council makes the following recommendations:

### ENACT STANDARD PRACTICE GUIDELINES

The National Institute of Mental Health division of the National Institute of Health, the PANDAS/PANS Collaborative Consortium, and the PANDAS Physicians Network have established diagnostic and treatment guidelines that have been published and are now being employed by numerous experts and relevant practicing physicians throughout the country. The council is recommending the standardization of care as reported here. We recognize that medicine is an ever changing and evolving field, and as such, we also recommend the members of this council stay up to date on any new science, research, and protocols to advise as needed.

### DEVELOP MECHANISMS TO INCREASE PUBLIC AWARENESS

- Assist IDPH, DHS, and other pertinent government agencies in creating awareness campaign materials appropriate for doctors' offices and public health clinics.
- Request assistance from the Illinois State Medical Society, the Illinois American Academy of Pediatrics, and other professional societies to disseminate educational materials.
- Encourage any appropriate state agencies to provide an educational tab about PANDAS/PANS on their respective websites, or link to the IDPH tab, as well as local resources (treating physicians, support organizations).
- Participate with the PANDAS/PANS Advocacy of Illinois and assistance from the PANDAS/PANS Clinical Research Consortium in the development of CEU/CME online training for pediatricians, mental health providers, and first responders/emergency departments.
- Investigate the possibility of bringing a PANDAS/PANS Center of Excellence to an Illinois teaching hospital to facilitate prompt recognition and treatment of PANDAS/PANS to ease the burden on the State.
- Hold another PANDAS/PANS Summit in 2019. Location to be determined. The meeting will pull together individuals from the various specialty areas involved in dealing with children and families impacted by PANDAS/PANS, and will continue to develop solutions for them. Education on the published treatment guidelines, new science, and the development of treatment resources should address the ongoing challenges of educating health care providers, educational professionals and families about PANDAS/PANS.
- Create templates and pocket cards to facilitate easier diagnostics and record keeping for physicians.
- Develop a flowchart, with the assistance of the Department of Insurance and the Department of Labor, for families and doctors to more easily navigate the insurance process.
- Invite a member of the Illinois Chapter of the American Academy of Pediatrics and a member of the Illinois State Medical Society to attend council meetings.

### PROVIDE OUTREACH TO EDUCATORS AND PARENTS

- Assist IDPH, DHS, the Illinois State Board of Education, and other pertinent government agencies in creating awareness campaign materials appropriate for school nurses, school social workers, school psychologists, and school administrators.
- Continue to encourage the use of strep notices and written explanations of school policies regarding reporting of classroom illnesses and healthy practices to avoid the spreading of disease. Consider basic information on PANS/PANDAS to be added to parent handbooks.
- Increase understanding of available support organizations for families through participation in state agencies' special events, such as IDPH's School Health Days.

- Provide professional development for teachers and administrators.
- Collaborate with Illinois Virtual Schools to promote online learning opportunities for children with PANS/PANDAS.
- Promote the use of the Illinois Attorney General's Office Healthcare Bureau to handle issues pertaining to consumer issues on health care accessibility.

### **INCREASE UNDERSTANDING OF THE BURDEN ON ILLINOIS**

- Have IDPH gather data and surveillance of incidence statistics on PANDAS/PANS and its co-occurring conditions such as Autism Spectrum Disorder, Immune Deficiencies, or other autoimmune conditions in children.

The council will continue to work on its commission to review recommendations concerning standard practice guidelines for PANDAS/PANS; develop mechanisms to increase clinical awareness of PANDAS/PANS; provide outreach to educators and parents; and develop a network of volunteer experts who can serve as resources within the state.

Council meetings in 2019 will be held bi-monthly at the IDPH Springfield and West Chicago offices. Call-in numbers are also available. For more information on scheduling, contact Nick Florian at [Nick.Florian@Illinois.gov](mailto:Nick.Florian@Illinois.gov) or Allison Nickrent at [Allison.Nickrent@Illinois.gov](mailto:Allison.Nickrent@Illinois.gov).

**In closing, PANDAS/PANS has long been a misunderstood condition. However, when it is estimated to affect approximately 1 in 200 children, its potential detriment cannot be ignored. The present available scientific evidence provides an excellent framework for the state of Illinois to impact the positive outcomes for these children and reduce the potential long-term physical and mental health consequences they may suffer.**

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