



PANS PANDAS

SCHOOL NURSE INFORMATION

PANS PANDAS in the School Setting

Pediatric Acute-onset Neuropsychiatric Syndrome

Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections



ASPIRE

Alliance to Solve PANS &
Immune-Related Encephalopathies

WHAT ARE PANS & PANDAS

PANS Pediatric Acute-onset Neuropsychiatric Syndrome

PANS is a clinical diagnosis based on history and physical examination. PANS diagnostic criteria require an acute onset or sudden worsening of OCD and/or restrictive eating, with concurrent symptoms in at least two of seven neuropsychiatric and somatic categories. Infections, metabolic disturbances, other inflammatory reactions, and stress can trigger PANS. Infectious triggers include upper respiratory infections, influenza, strep, mycoplasma pneumoniae, and Lyme borreliosis, among others. The average age of onset is between 3 and 13, but post-pubertal cases do occur. There is no requisite age of symptom onset for a PANS diagnosis.

PANDAS Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

PANDAS, a subset of PANS, is associated with group A Streptococcus (GAS) infections. Not all patients have a positive strep throat culture, and examination must be followed by ASO and ADB immune responses. The onset of symptoms can occur within days of contracting strep, or within several months.

PANS/PANDAS are misdirected immune responses, often with an encephalitic onset, resulting in acute onset of OCD, tics, and/or restricted food intake, along with other neuropsychiatric and somatic symptoms. After the initial onset, PANS/PANDAS symptoms follow a relapsing/remitting course. Initial triggers may differ from secondary triggers. During each recurrence, symptoms can worsen, and new symptoms may manifest. Symptoms can range from mild to severe. In mild cases, children might function well enough to continue to attend school. In severe cases, symptoms can become life-threatening due to extreme food restriction and/or suicidality. Many children with PANS/PANDAS are diagnosed with a psychiatric illness and prescribed psychotropic medications rather than evaluated and treated for an underlying infection. According to a consortium of experts convened by the National Institute of Mental Health, appropriate treatment for these disorders is a triad that incorporates psychological support (CBT, ERP, and/or psychotropic medication), antimicrobial treatment, and immunomodulation.

PANS

is caused by an infectious trigger or other non-infectious agents.

PANDAS

is associated with group A Streptococcus (GAS) infections.

PANS PANDAS DIAGNOSTIC EVALUATION & TREATMENT GUIDELINES

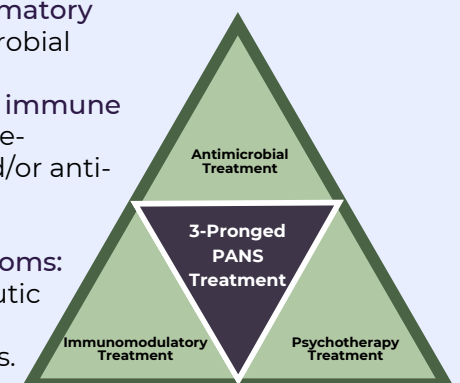
Diagnostic Criteria for PANS

- Abrupt, acute onset of
 - Obsessive-Compulsive Disorder or
 - Severely Restricted Food intake
- Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven following categories:
 1. Anxiety, separation anxiety
 2. Emotional lability or depression
 3. Irritability, aggression, and/or oppositional behaviors
 4. Behavioral or developmental regression
 5. Deterioration in school performance
 6. Sensory or motor abnormalities, tics
 7. Somatic signs: sleep disturbances, enuresis, or urinary frequency
- Symptoms are not better explained by a known neurologic or medical disorder
- Age requirement – None

Three Modes of Treatment

“Treatment of PANS involves a three-pronged approach that utilizes psychiatric medications when appropriate to provide symptomatic relief, antibiotics to eliminate the source of neuroinflammation, and anti-inflammatory and immune modulating therapies to treat disturbances of the immune system.”

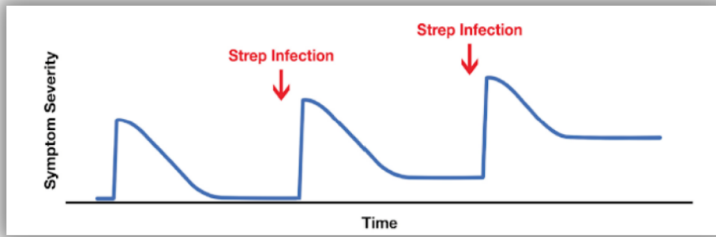
- **Remove inflammatory source:** antimicrobial treatments.
- **Treat disrupted immune system:** immune-modulating and/or anti-inflammatory interventions.
- **Alleviate symptoms:** psychotherapeutic treatments, psychotherapies.



Overview of Treatment of PANS-JCAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

UNDERSTANDING SYMPTOM PATTERNS

Repeated Flares & Symptom Baseline



Source: NIMH Information About PANS/PANDAS
<https://www.nimh.nih.gov/research/research-conducted-at-nimh/research-areas/clinics-and-abs/sbp/information-about-pans-pandas.shtml>

PANS symptoms can relapse and remit. Some symptoms do not return to baseline between flares, while others are only reduced. In some cases, subsequent flares can be more severe with a longer duration and become chronically debilitating. PANS symptoms can remit completely, especially if treated quickly and thoroughly. Treatment plans should clear the current flare but also address ongoing symptoms. The goal is to relieve symptoms and prevent them from becoming chronic.

PANS Symptom Severity

The severity of PANS symptoms varies from patient to patient and can vary from flare to flare. Treatment plans reflect the severity of the current PANS flare and case history.

Mild Symptomology

- Symptoms interfere with daily life but not in all settings
- Able to attend school but with separation anxiety
- OCD occupies 1-2 hours a day without escalating to obsessional fears
- Other symptoms vary from patient to patient and from flare to flare but are not incapacitating
- Symptoms require some school accommodations

Moderate Symptomology

- OCD occupies 50%-70% of the waking day. Impacts daily activities severely but not fully disabling
- Other symptoms are also moderate; impact daily life but not incapacitating
- School attendance may be affected, but the patient may be able to engage in other activities
- Symptoms require increased school accommodations and supports

Severe Symptomology

- Neuropsychiatric symptoms can result in life-threatening situations
 - Hazardous impulsivity and/or regression
 - Weight loss (>10%-15% of body mass) due to obsessional food restrictions
- OCD, anxiety and fears occupy 80%-100% of waking day
- Unable to attend school due to OCD and separation anxiety
- Irritability, depression, aggression, and other symptoms can be equally present

10 Things You Should Know About PANS/PANDAS

1. **Strep throat is NOT the only infectious trigger.** Although group A streptococcal (GAS) infections are associated with PANDAS, PANS is a broad-spectrum syndrome that can result from a variety of disease mechanisms and multiple etiologies.

2. **Acute onset can be preceded by milder episodes.** Mild cases have been documented, and symptoms might look like behavioral problems, isolated tics, and sensory issues, among other issues that require awareness on the part of the parent and provider. These children should be clinically evaluated for PANS/PANDAS.

3. **Tics are not always present.** While tics were part of the original PANDAS diagnostic criteria, they are not required for a PANS diagnosis.

4. **OCD symptoms vary.** While the mean onset age of OCD in children is between the ages of 9 and 10, it can start much earlier in children with PANS/PANDAS. OCD presentation is acute and disruptive to a child's normal functioning.

5. **Restrictive eating can be a primary symptom.** Some children with PANS/PANDAS present with Avoidant Restrictive Food Intake Disorder (ARFID) without OCD or tics. A child with severe food restriction resulting in dramatic weight loss or who refuses fluid intake should be examined for PANS/PANDAS.

6. **Children with PANS/PANDAS may experience recurrence of episodes.** Some children experience remission of symptoms after treatment with no recurrence, while a portion experience subsequent exacerbation (relapse) incited by a variety of triggers.

7. **Prevalence is unknown due to poor diagnosis.** PANS/PANDAS affects as many as 1 in 200 children each year, according to the PANS/PANDAS consortium.

8. **Scientific studies strongly support PANS/PANDAS diagnosis.** Diagnostic guidelines published by the Journal of Child and Adolescent Psychopharmacology (July 2017) and a recent nationwide survey in the

Netherlands designed to test the PANDAS hypothesis demonstrated that individuals with a positive a streptococcal test have an increased risk of neuropsychiatric disorders. The study also showed an increased risk of non-streptococcal throat infections.

9. **Early diagnosis and treatment lead to improved outcomes.** According to NIMH, "preliminary data suggest that with appropriate treatment early in the course of illness, and effective use of antibiotic prophylaxis, we may be able to prevent up to 25%-30% of childhood mental illnesses".

10. **Pediatricians CAN diagnose and treat PANS/PANDAS.** The 2017 JCAP Treatment Guidelines issued by the PANS Physician Consortium provide practical clinical recommendations for the management and treatment of children diagnosed with PANS/PANDAS.

School Impact

PANS is a medical condition affecting a student's ability to attend school and learn by impacting physical, psychological, neurological, behavioral, and developmental health. Treatment includes medical protocols as well as therapeutic practices. School accommodations are an essential component of an appropriate treatment protocol.

Impacts Multiple Areas of Learning

PANS symptoms impact multiple areas of learning: academic, cognitive, behavioral, and physical. Some PANS students will be affected more severely than others; some will have a small concentration of symptoms, while others will exhibit symptoms across all domains.

Individualized Accommodations

Most students require individualized accommodations (IEP, 504, IHCP, or non-formalized supports built into the classroom). The level of support depends upon the severity of symptoms. The ASPIRE website has a list of commonly utilized accommodations across multiple learning domains. Accommodation and supports help students remain functional during a flare. Remedial support between flares can help a student regain skills lost during a flare.

There is no 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 with fluidity in and out of services. Plans should be written with the student's worst days in mind while hoping for the best days. A student may present with one or more primary symptoms, which may resolve only to be replaced with a new set of symptoms at the onset of a new flare.

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. Caution must be taken not to 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.

Frequent Absences

School refusal is seen in probably 90-100% of PANS students, often due to separation anxiety and OCD. In a qualitative study, half of the PANS students were placed for a period of time in home-hospital services or were homeschooled. The main reasons for absences are separation anxiety, OCD, sleep disturbances, fatigue, immune and health issues, and doctor's appointments. A student's functioning may change rapidly, requiring a smooth and quick transition in and out of services.

Accommodations should include allowances for absences, late arrival, and early dismissal. Modifying schedules should be considered on an as needed basis. Explore flexible supports that weave together partial school day schedules, online learning, and in-home tutoring during times of acute flares. Planning teams should create reentry plans for those who have missed a significant amount of time. Do not assume a student is back to normal functioning because they are attending school. Pushing too hard for normalcy may result in a backslide.

Multiple Domains of Learning Impacted

Academic/Cognitive Symptoms

- Loss of math skills
- Decline in handwriting skills
- Reduced concentration
- Perfectionism
- Work refusal
- Reduced memory
- Avoidance of high sensory settings
- Decline in creativity
- Inability to make decisions
- Reduced ability to focus
- Poor organizational skills
- Time management problems
- Difficulty in planning & prioritizing
- Visual processing difficulties
- Processing delays

Physical/Sensory/Motor Symptoms

- Restricted food intake: fear of contamination, choking, sensory
- Tics: Vocal and/or motor
- Urinary frequency & involuntary urination
- Unusual gait & Balance issues
- Hair pulling and skin picking
- Dilated pupils
- Stomach pain
- Fatigue
- Hallucinations
- Selective mutism
- Frequently sick
- Low tone

Behavioral Symptoms

- Obsessive thoughts: rigidity, perfectionism, inappropriate Compulsive actions
- Anxiety: separation, school refusal, general
- Depression & emotional lability
- Aggression: oppositional behavior, rages
- Regression: immaturity, baby talk
- ADHD: poor impulse control, fidgeting, outbursts
- Sensory issues: defense and seeking

SCHOOL NURSES & PANS PANDAS

School Nurses play an integral role in the health of students. They support students and student health every day of the year. Children with PANS/PANDAS have complex physical and mental health conditions that benefit from a School Nurse's support.

School Nurses connect providers, parents, & school staff working to bolster student attendance and wellness. A School Nurse can coordinate care between the child's health care providers, other staff, and parents, so their health needs are met and ready to learn. Taking the time to communicate and collaborate as a team is a key part of ensuring a PANS/PANDAS student's success.

"The school nurse, as a member of a multidisciplinary team, benefits from an awareness of these disorders, the resulting impact on school performance, and the recommended treatment."

- Kathy Bagian, MSN, RN, CSN, Sheila Q. Hartung, PhD, RN, *Is It PANS, CANS, or PANDAS? Neuropsychiatric Pediatric Disorders That Are Not Black and White—Implications for the School Nurse*

Unique Position of the School Nurse

- May be the first person to establish a link between a recent or recurring strep infection with a sudden onset of atypical behavior
- Can help report any abrupt changes in behavior, eating habits, or school performance to the family
- Can inform parents of any communicable illness in classrooms
- Can help develop and monitor attendance places and IHP/IHCP
- May be the person who knows the student better over time

School Nurse Role

- **Bridge communication** between staff, parents, and outside providers
 - Develop and monitor Individual Healthcare Plans (IHP/IHCP)
 - Provide guidance to the team developing 504 and IEP plans
- **Infection Control** - Communicate with family and school community about strep and other infectious illness (mycoplasma pneumonia, Coxsackie, impetigo, etc.)
 - Provide ideas for reducing infection spread in the classroom
 - Send Notification of Strep or Other Infection letters to the school community
 - Inform parents of PANS/PANDAS students if strep or a particular illness is going around the school
 - Request that the school community informs the School Nurse office of strep or other illness.
- **Educate** the school community on PANS/PANDAS
 - Share information via newsletter, website, and school meetings, etc.
 - Refer students to their primary care provider if you suspect PANS/PANDAS
- **Provide emotional support** to parents and student

INDIVIDUALIZED HEALTH CARE PLANS

The Individualized Healthcare Plan (IHP/IHCP) is a healthcare plan adapted for the school setting. An IHP/IHCP provides the framework to ensure the school addresses a student's medical needs correctly during the school day. The need for IHP/IHCP is contingent on a student's need for nursing care at school or during a school activity. It is not based upon educational needs addressed in 504 or IEP plans. Students with an IHP/IHCP may need an Emergency Care Plan (ECP) also. An IHP/IHCP may be included in an Individualized Education Program (IEP) or 504 Plan.

Parents Should Bring to an IHP/IHCP Development Meeting

- Contact information of the primary doctor and specialists.
- Consider signing waivers for school and doctors to communicate with each other as necessary.
- Doctor's orders and other instructional materials
- Information regarding the child's condition and healthcare needs

The IHP/IHCP is developed by the school nurse with the parents, student (if appropriate), relevant school personnel, and the student's healthcare provider/s. An IHP/IHCP will contain information on the student's condition and health needs. It will list who is responsible for monitoring specific health needs at school and during transport to and from school, field trips, or school-sanctioned after school activities. Proper, proactive planning by school officials and parents of a detailed IHP/IHCP can help to keep a student with special health needs safe at school and during school activities.

Individual Health Care Plans Should Include

Many factors need to be included when developing an individualized healthcare plan. It is important to remember that this plan applies uniquely to the student and the current issue they are dealing with.

- Creates solutions to potential health problems that can occur in a school environment to ensure the school is a safe environment that helps students learn.
- Consider the student's whole day and what exemptions and accommodations need to be made in different situations.
 - Classroom, lunch/recess, transportation, field trips, physical education, extracurricular activities
- Include Nursing Diagnosis – functional health issues
- Include Objectives/Goals for the student to promote self-care and age-appropriate independence
- Ensure that the school has relevant information and authorization regarding medical information about student
- Addresses both family and school concerns
- Clarify roles and responsibilities
- Establish a basis for ongoing teamwork, communication, & evaluation

INDIVIDUALIZED HEALTH CARE PLANS

Sample IHCP/IHP

Not all accommodations or considerations are appropriate for every student. The information in the following sample IHP/IHCP is pulled from the IHP/IHCPs of several PANS/PANDAS students but does not include every possible consideration. IHP/IHCPs should be written on individual student's needs. For more examples, please see the two-page IHP sample pages at www.aspire.care/schools-educators/school-nurse-role

Nurses Diagnosis	Student Goal	Intervention	Who/When	Why
PANS symptoms relapse and remit. Medical needs may vary during school year.	NA	<ul style="list-style-type: none"> Parents to review and update the health history assessment each school year or more frequently if changes occur Parents will inform school nurse of any planned IVIGs other medically necessary interventions requiring days off from school. Medications at School: Obtain health care provider authorization. Obtain Medical Supply. Maintain medication administration record. 	Parent & School Nurse/As Needed	<ul style="list-style-type: none"> To promote health and well-being. Not all symptoms are seen at school as not all are seen at home; open communication is critical to addressing flares early and consistently
See Above	NA	Notify parent of any changes in student's condition	Nurse/As Needed	See Above
See Above	NA	School Staff and School Nurse will recognize signs of PANS episode	School Staff & Nurse	See Above
Biodefense related to: Increased susceptibility of PANS flare from contact with any infectious disease.	NA	Share/exchange health information with parent with regard to communicable diseases in classroom	Nurse/As Needed	To promote health and well-being. Potential for flare related to compromised immune system. Decrease chance of cross contamination
See Above	Student will learn hand washing & hygiene.	School Staff to provide education on proper hand washing and basic hygiene to prevent spread of infections.	Nurse/As Needed	See Above
Separation Anxiety & Fear – Related to OCD and inability to predict or control symptoms.	Student will attempt to identify and utilize calming techniques	<ul style="list-style-type: none"> Work with counselor on techniques while not anxious to build toolbox. Provide anytime pass to Safe Place. Track times used If symptoms are not resolving, not able to work to school expectations, notify parents ASAP Refrain from criticism, shaming 	School Counselor/ Weekly Sessions	To create a bank of calming techniques so symptoms do not escalate.
Frequent absences, brain fog, short-term memory loss and regression in skills make keeping up with schoolwork hard; more support needed.	Will work with teachers to identify how & when to access more support & select activities.	Option to not participate in select elective programs in order to meet with academic teacher/s for more help or work on homework.	School Staff/As Needed	To promote health and well-being and increase access to curriculum.
Tics are a common symptom of PANS/PANDAS	Student will learn how to access Anytime Pass if tics become too distracting.	<ul style="list-style-type: none"> Classroom support for tics that are bothering student Provide anytime pass to Safe Place. Track times used 	School Staff & Nurse/As Needed	Minimize disruptions to class and embarrassment of student over symptoms
Ineffective Coping – Related to knowledge deficit of school resources, possible reluctance to seek help.	Student will identify support systems and when and how to utilize Anytime Pass to access "Safe Place".	<ul style="list-style-type: none"> Check in when student shows signs of frequent bathroom breaks, putting face in hands, picking at own hands or other different behaviors. Track times used If student is unable to recognize when they need to use it, teacher should learn how to do so. 	School Staff & Nurse/As Needed	These could be indications of OCD or anxiety. Stress needs to be minimized.
Aggression/Rage, Depression, Emotional Lability – Related to PANS Symptoms	See Above	<ul style="list-style-type: none"> Student becomes sad or angry without due cause Provide anytime pass to Safe Place. Track times used If symptoms are not resolving, not able to work to school expectations, notify parents ASAP Refrain from criticism, shaming 	School Staff & Nurse/As Needed	To promote health and well-being

Our Mission

To improve the lives of children and adults affected by PANS, PANDAS, and immune-related encephalopathies.

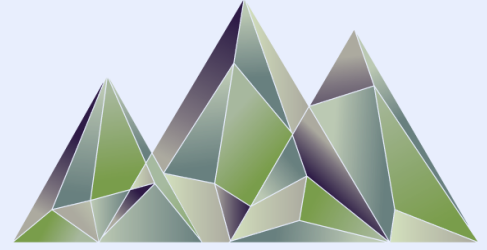
Our Vision

We aspire to create a world where children and adults affected by PANS, PANDAS and related encephalopathies obtain a timely diagnosis from informed providers and receive effective, proven and affordable treatments and support in all areas of daily living, without discrimination.

Who We Are

We are experienced leaders in the PANS advocacy community. We are parents, providers and experts in our field who believe collaboration and empowered action are the keys to the world we seek: one where no one suffers through PANS and immune-related encephalopathies without access to a knowledgeable provider, insurance coverage for standard-of-care treatments or the support that comes with public awareness.

We work collaboratively to improve the quality of life for those affected by PANS, PANDAS and immune-related encephalopathies. We focus our efforts on empowering and connecting our community with tools and resources for advocacy, education, support, and awareness.



ASPIRE

Alliance to Solve PANS & Immune-Related Encephalopathies

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SCHOOL NURSES & PANS/PANDAS

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Open communication is needed during the development of the IHP/IHCP between parents/guardians, administrators, teachers, and the school nurse. Students who are an appropriate developmental age should participate in developing the IHP/IHCP.

Individual Health Care Plans Should Include

Many factors need to be included when developing an individualized healthcare plan. It is important to remember that this plan applies uniquely to this Student and the current issue they are dealing with.

- Creates solutions to potential health problems that can occur in a school environment to ensure the school is a safe environment that helps students learn.
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Sample Individualized Health Care Plan

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See Above	NA	Notify parent of any changes in student's condition	Nurse/As Needed	See Above
See Above	NA	School Staff and School Nurse will recognize signs of PANS episode which include behaviors such as motor and vocal tics, headaches, drooling, anxiety, mood swings, OCD, ADD, ODD, depression, irritability, behavioral regression, deterioration in school performance, sensory issues, urinary frequency.	School Staff & Nurse/Start of each year	See Above
Biodefense related to: Increased susceptibility of PANS flare from contact with any infectious disease.	NA	Share/exchange health information with parent with regard to communicable diseases in classroom	Nurse/As Needed	To promote health and well-being. Potential for flare related to compromised immune system. Decrease chance of cross contamination
See Above	Student will learn to wash hands and basic hygiene.	School Staff to provide education on proper hand washing and basic hygiene to prevent spread of infections.	Nurse/As Needed	See Above
See Above	Student will learn to limit sharing of materials.	Promote health by decreasing shared objects at school	School Staff/As Needed	See Above
See Above	NA (Unless appropriate for student to clean station.)	Promote health by cleaning work spaces at school	School Staff/Daily/before Student comes into room	See Above
See Above	NA	Promote health by teaching proper sneezing/coughing techniques to ALL students	School Staff & Nurse/As Needed	See Above
See Above	Student will learn to not use water fountains. Parents will supply clean water bottles; student allowed to keep a water bottle.	School Staff will understand that student is not to use water fountains.	School Staff & Nurse/As Needed	See Above



Sample Individualized Health Care Plan

Page 2

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Tics are a common symptom of PANS/PANDAS	Student will learn how to access Anytime Pass if tics become too distracting.	<ul style="list-style-type: none"> Classroom support for tics that are bothering student Provide anytime pass to Safe Place. Track times used 	School Staff & Nurse/As Needed	Minimize disruptions to class and embarrassment of student over symptoms
Ineffective Coping – Related to knowledge deficit of school resources, possible reluctance to seek help.	Student will identify support systems and when and how to utilize Anytime Pass to access “Safe Place”.	<ul style="list-style-type: none"> Check in when student shows signs of frequent bathroom breaks, putting face in hands, picking at own hands or other different behaviors. Track times used If student is unable to recognize when they need to use it, teacher should learn how to do so. 	School Staff & Nurse/As Needed	These could be indications of OCD or anxiety. Stress needs to be minimized.
Separation Anxiety & Fear – Related to OCD and inability to predict or control symptoms.	See Above	<ul style="list-style-type: none"> Student shuts down/ is unable to speak Provide anytime pass to Safe Place. Track times used If symptoms are not resolving, not able to work to school expectations, notify parents ASAP Refrain from criticism, shaming 	School Staff & Nurse/As Needed	To promote health and well-being
Aggression/Rage & Depression/Emotional Lability – Related to PANS Symptoms	See Above	<ul style="list-style-type: none"> Student becomes sad or angry without due cause Provide anytime pass to Safe Place. Track times used If symptoms are not resolving, not able to work to school expectations, notify parents ASAP Refrain from criticism, shaming 	School Staff & Nurse/As Needed	To promote health and well-being
Separation Anxiety & Fear – Related to OCD and inability to predict or control symptoms.	Student will attempt to identify and utilize calming techniques	<ul style="list-style-type: none"> Work with counselor on techniques while not anxious to build toolbox. Provide anytime pass to Safe Place. Track times used If symptoms are not resolving, not able to work to school expectations, notify parents ASAP Refrain from criticism, shaming 	School Counselor/Weekly Sessions	To create a bank of calming techniques so symptoms do not escalate.
Fatigue is associated with PANS; being ill can lead to fatigue. Some medication can exacerbate fatigue		<ul style="list-style-type: none"> Fatigue; student may require time to rest or a healthful snack. School Staff will understand that Student might require snacks between meals in order to sustain energy. Student is allowed to use Elevator 	School Staff/As Needed	To promote health and well-being
Sensory abnormalities are a common symptom of PANS		<ul style="list-style-type: none"> School Nurse will provide access to cold or hot compresses. School Staff will understand that Student might need to wear a hat with a brim to aid in light sensitivities. 		To promote health and well-being
Frequent absences, brain fog, short-term memory loss and regression in skills make keeping up with schoolwork	Will work with teachers on identifying times to access more support and choose which activities they are able to miss.	Option to not participate in select elective programs in order to meet with academic teacher/s for more help or work on homework.	School Staff/As Needed	To promote health and well-being and increase access to curriculum.