PANS/PANDAS Consultation Checklist

NOTE: Please fill out to the best of your ability and bring a copy to the consultation visit.
Form can be returned via:
E-Mail: susankschulmanmd@gmail.com (Include child's name and DOB in the Subject)
Fax: ATT: Susan Schulman → (718) 435-6188
Mail: ATT: Susan Schulman → 901 48th street Brooklyn NY, 11219
If you are returning it by mail please make a copy prior to sending it

Informants Name: Relationship to Patient:

Name: DOB: Date of consultation:

Allergies:

Current Medications (concentration and dose):

How many siblings does the child have and where do they fit into the family?

Past Medical History:

Past Surgical History:

Has he ever had a tonsillectomy and or adenoidectomy? Y N ❑ COMPLETE ❑ PARTIAL ❑ SHAVED Date:

Family History of psychiatric or autoimmune disease:

Parents Marital Status: Father's Occupation: Mother's Occupation:

Home Stressors:

What kind of school is the child in? Grade:

Special Services: School Performance:

Extra-Curricular Activities:

Special Talents (ie: art, music, sports, dance, other):

Screen time per day – Weekdays: Weekends: Video games? Y N

BASELINE PERSONALITY

Describe your child prior to the onset of symptoms:

Check all that apply:

❑ Good Natured	❑ Generally Happy	❑ Obedient	❑ Generous	❑ Easygoing
❑ Shy	❑ Anxious	❑ Strong Willed	❑ Hard Worker	
❑ Outgoing	❑ Orderly Nature	❑ Has Friends	❑ Kind Hearted	

CHIEF COMPLAINT

When did the symptoms start? ❑ Sudden ❑ Gradual Approximate Date:

Any illness within 6 weeks prior to onset?: ❑ Yes ❑ No Describe:

History of multiple strep throats? ❑ Yes ❑ No Treatments?:

Brief Description of symptoms at onset and currently:

Does anything make it better or worse? ❑ Yes ❑ No Describe:

CHECK AND DESCRIBE ALL SYMPTOMS THAT APPLY: PLEASE SEE PAGES 3-5 FOR AN EXPLANATION OF EACH CATEGORY:

OCD:

❑ **Compulsive behaviors or Rituals** ❑ **Intrusive Thoughts** ❑ **Obsessive Feelings**

Describe:

RESTRICTIVE EATING:

❑ **Eating disturbances**

Describe:

ANXIETY:

❑ **Generalized Anxiety** ❑ **Separation Anxiety/ Clinginess**

❑ **School Refusal** ❑ **Particular New Fears**: (Ex: Fear of vomiting, fear of being alone etc.)

Describe:

EMOTIONAL LABILITY AND/OR DEPRESSION:

❑ **Labile** (Ex: Unpredictable Mood Changes) ❑ **Sad or Down**

Describe:

IRRITABILITY, AGGRESSION, AND/OR SEVERE OPPOSITIONAL BEHAVIORS:

❑ **Irritability** ❑ **Aggression/ Violence** (Ex: Does he hurt anybody or damage things etc)

❑ **Anger Outbursts/Tantrums** ❑ **Oppositional Behavior** (Ex: Difficulty obeying authority etc)

Describe:

BEHAVIORAL (DEVELOPMENTAL REGRESSION):

❑ **Regression** (Ex: Babyish language or behavior etc)

Describe:

SUDDEN DETERIORATION IN SCHOOL PERFORMANCE:

❑ Deterioration in School Work/Grades ❑ Language Skills ❑ Math ❑ Reading

❑ Deterioration in Handwriting ❑ Difficulty Concentrating ❑ Decrease ability to learn and/or Retain Knowledge

❑ **Brain Fog**: Describe (Clouding of memory and/or Perception) ❑ Other

Describe:

MOTOR OR SENSORY ABNORMALITIES:

❑ **Motor Tics** (Ex: Eye, Face, Neck, Shoulder, Other)

❑ **Vocal Tics** Describe (Ex:Humm, Snort, Sniff, Cough, Throat Clearing, Laugh, Blurting/ Repetitive Sounds, Other)

❑ **Sensory Irritability** (Ex: Clothing, Sounds, Touch, Smell, Other)

Describe:

SOMATIC SIGNS AND SYMPTOMS INCLUDING SLEEP DISTURBANCES, ENURESIS, OR URINARY FREQUENCY:

Sleep Disturbances:

❑ **Falling Asleep** ❑ Staying asleep ❑ Poor Quality of Sleep

❑ **Sleep Disturbances** (Nightmares/Night Terrors) **Average Number of Hours A Night?:**

Describe:

Urinary Problems:

❑ **Frequency** ❑ **Bedwetting** ❑ **Day Wetti**ng

Describe:

OCD

- There are many different types of obsessions and compulsions, and a complete listing is not possible here. Many medical professionals assume OCD is repetitive hand washing. However, OCD consists of many types of obsessions and compulsions. For a full description of OCD, please see the International OCD Foundation website (www.iocdf.org) and the Y-BOCS Symptom Checklist, which includes a comprehensive list of 67 types of obsessions and compulsions. A short, but not full, list of OCD symptoms includes:
  - Contamination obsessions (germs, bodily secretions or waste, poisons, animals, environmental contaminants like tobacco, cleansers or any substance). Often, the obsession leads to compulsive washing or cleaning rituals; but, in some cases, the symptoms cause the child to avoid the feared contaminant. In severe cases, even a loving parent may be a contaminant because of "exposure" to the dirty object, and the child will develop complex rituals to avoid contact with the exposed parent.
  - Sexual or religious obsessions (fear that God hates them or that they have done something morally offensive)
  - Aggressive obsessions of harm to oneself or others
  - Repeating compulsions (examples: going in and out of a doorway; switching on/off appliances or light switches; re-reading pages over and over)
  - Symmetry and exactness obsessions (examples: books and papers must be properly aligned; every action has to be done exactly the same on the right and left side; the child has to walk exactly in the center of a hallway)
  - Ordering / arranging compulsions (example: suddenly placing bathroom items in a particular order and extreme anxiety if they are moved)
  - Counting compulsions (examples: having to count ceiling tiles, books, or words spoken)
  - Checking compulsions and requests for reassurance (examples: repeatedly asking a parent "is this okay?" or "did I do that right?")
  - Need to touch, tap, or rub (examples: rubbing the back of one's hand across the table in a certain way, urge to touch rough surfaces)
  - Intrusive images, words, music or nonsense sounds (examples: unwanted images, words, or music appear in the mind that do not stop)
  - Need to tell, ask, or confess (examples: child needs to tell parent every perceived mistake or sin that day in school; excessive guilt)
  - Colors, numbers, or words with special significance (examples: the color black is equated with death and anything black triggers obsessional fears; the number 3 is "lucky" and things have to be repeated three times or 3X3X3 times)
  - Ritualized eating behaviors (examples: eating according to a strict ritual; not being able to eat until an exact time)
  - Hoarding behaviors (Obsessional concerns about losing something important generalize to the point where nothing can be thrown away, or useless items take on special significance and cannot be discarded.)

Restrictive eating

- Approximately 1 in 5 children with PANS will have restricted intake of specific foods or all food groups, often with observable weight loss and occasionally with dehydration, if fluid intake is also affected. The underlying symptom may be contamination fears associated with the food itself or what the food may have been exposed to. In some cases, obsessional fears of choking or vomiting may drive the eating restrictions. In other cases, the child refuses to eat because he fears harm will come to himself or others, such as his parents, if he eats; in these cases, the child may be afraid to speak of the association because of additional obsessional fears. Lastly, the patient may refuse to eat because of a new obsession with body image or weight. The acuity of symptom onset and age at onset can distinguish PANS-related eating restrictions from more typical anorexia nervosa.

Anxiety (heightened anxiety, separation anxiety, irrational fears)

- The child may develop generalized anxiety, where he or she begins worrying about everything from the color of the sky ("How do I know that it's really blue?") to his health and well-being ("I don't feel very good. Am I going to die today?") If a child is a "worrier" by nature, there must be an abrupt and noticeable increase above baseline anxiety levels. His or her anxiety becomes consistent and increasingly disabling. Separation anxiety is also common in PANS. A previously independent child who had no problems going to his room alone, going to bed alone, or wandering away from his parents in public places, will suddenly refuse to enter his room alone, needs to sleep in his parents' bed at night, and clings to his parent's side in public. Even at home, the child may seek physical closeness from family members or require constant reassurance about his safety. The child may also begin questioning his own judgment and behavior, constantly asking his parent if it is okay to do routine activities. In some cases, the separation anxiety extends to inanimate objects. A child who never paid attention to the furniture may burst into tears when a table or couch is removed for sale.
- The patient may also develop new phobias or irrational fears. The fears may interfere with the child's ability to function at school, home, or with his friends. For example, he might develop a fear that he is going to get cancer and will refuse to let his mother use cleaning chemicals. Or, the child may develop fears of electrocution and refuse to walk outside because of nearby electrical wires. In other cases, there appears to be no rational basis for the phobias, such as a child who becomes deathly afraid of sitting next to a particular classmate. Children may have such overwhelming fear that they have increasingly narrow "safe zones"; in severe cases, refusing to leave their parents' room or even their bed.
- The child may develop panic attacks, with feelings of terror or dread, and physical symptoms, such as dilated pupils, racing heart, and dry mouth. Often, the "terror-stricken" look becomes part of their regular countenance, and the child seems to be continuously miserable.

Emotional Lability or Depression

- An even-keeled, happy-go-lucky child may suddenly undergo a dramatic personality change and become excessively moody and emotionally labile. The child may burst into tears over problems that prior to onset would not elicit such a response. Emotionally labile children experience sudden and unexpected changes in mood, shifting from laughter to tears or anger without an obvious precipitant. The child might complain that he has an inner sense of restlessness and agitation, which is similarly inexplicable.
- Some patients may experience the abrupt onset of clinical depression. A child might say "I'm not a good person," but may also become so severe that the depression is accompanied by suicidal ideation. Self-injurious behaviors and suicidal ideation are also common and of particular concern among children with concomitant impulsivity and behavioral regression, as they may injure themselves or others. The constant battle with their own thoughts and comorbid symptoms may lead to depression until they ask "why is life worth living?"

Aggression, Irritability and Severe Oppositional Behaviors

- These symptoms often top the list of parental concerns because they are so disruptive. The irritability and oppositional behaviors are present throughout the day, and the aggression occurs without provocation or precipitant. Most notable is the striking contrast between these new behaviors and the child's usual state of being "sweet-tempered and well-behaved" or "easygoing and well-liked". For example, a boy who has been close to his mother may suddenly begin attacking her physically, trying to hurt her. Some children recognize their irrational behavior and experience remorse after the attacks; others have no memory of the episode or their behavior. Outbursts occurring in response to interruption of an obsessional thought or compulsive ritual should not be counted as a manifestation of this category, as they are an expected occurrence among pediatric patients with severe OCD.

Behavioral (Developmental) Regression

- The symptoms of developmental regression include an abrupt increase in temper tantrums, loss of age-appropriate language (sometimes to the point of the child using "baby talk"), and other behaviors inappropriate to the child's chronological age and previous stage of development. The developmental regression may be most apparent in the child's school assignments or artwork. Sometimes, symptoms of separation anxiety belong in this category, rather than with the anxiety disorders. The child may regress to the "clingy" stage, where he needs to be physically close to one of his parents at all times. If the separation anxiety is a manifestation of behavioral regression, it should not also be counted as an anxiety disorder.

Sudden Deterioration in School Performance

- A number of factors may contribute to the child's academic difficulties, including, among others, a shortened attention span, difficulties with concentration or memorization, and other disturbances of cognition and executive functioning. For example, a child previously may have been able to concentrate for hours on an art project, but now can focus for only a few minutes at a time. Math skills often decrease from previous levels, and children have been reported to develop new deficits of visuospatial skills.
- The child may develop a number of ADHD-like symptoms, including impulsivity, inattention, and motoric hyperactivity. A child who has a high level of concentration in school or at-home activities suddenly can no longer sit still or concentrate. A child who may normally sit for a long period of time coloring his/her book can no longer stay seated longer than a few minutes. Conversely, a quick activity like tying one's shoes suddenly takes a long time due to focus issues. The anxiety coupled with the hyperactivity may result in a changed child who is constantly alert, fidgety, and on the move. As with the other categories, the academic difficulties must represent a distinct change from previous levels of functioning. Thus, manifestations of pre-existing attention deficit hyperactivity disorder (ADHD) or learning disabilities are not counted here, nor are long-standing deficits of visuospatial or fine motor skills.
- Patients in many studies score poorly on orthographic memory tests like the Rey-Osterrieth Complex Figure Test.

Motor and Sensory Abnormalities (touch, visual images, sound)

- Motor abnormalities include a variety of signs and symptoms, such as an abrupt deterioration of the child's handwriting (dysgraphia), clumsiness, tics, choreiform movements, motoric hyperactivity, and akathisia. Dysgraphia is a particularly useful diagnostic feature, as handwriting samples obtained during the child's acute illness can be compared against those produced during an asymptomatic period. This feature of the disorder can be used to identify precipitating infections by comparing longitudinally-collected handwriting samples with infections documented in the child's medical record. Asking the child to copy a complex picture such as a Rey-Osterrieth figure may also demonstrate abnormalities. Choreiform movements must be distinguished from choreoathetoid movements of Sydenham chorea. While chorea is characterized by jerky or writhing, arrhythmic, involuntary movements of the extremities, trunk, and facial muscles, choreiform movements are described as "fine, piano-playing movements of the fingers" that present only when the child maintains stressed postures such as arms stretched straight out, hands extended.
- All tics start suddenly. One day they are not there and the next they are. But certain tics are distinguishable by their intensity and interference with daily life. Complex tics or dramatic, debilitating tics are characteristic of PANS as well as PANDAS. Tics that existed prior to onset and continued at the same rate and intensity would not qualify as meeting this comorbid criteria.
- The sensory abnormalities may include a sudden increase in sensitivity to light, noises, smells, tastes, or textures. For example, the child may refuse to eat certain "stinky" foods, like cheese, or to wear scratchy, tight, or otherwise uncomfortable clothing, such as the waistband of underwear or socks. In other cases, the child may develop sensory-seeking behaviors, such as needing to touch or feel particular objects or textures.
- Visual hallucinations may also occur and might include frightening images and altered perceptions, such as objects that appear to be floating or to change size, appearing larger or smaller than their actual size. The visual hallucinations are usually brief, but may be more persistent, lasting for several hours or longer. Children have described these "nightmares while awake" as extremely disturbing and frightening, such as seeing their parents killed or injured by an intruder.

Somatic Signs and Symptoms Including Sleep Disturbances, Enuresis, or Urinary Frequency

- Sleep problems and disturbances of urination and micturition are among the most common physical manifestations of PANS. The sleep disturbances may include not only the new onset of terrifying nightmares and night terrors, but also difficulties falling asleep, staying asleep, or waking up too early (early, middle, or terminal insomnia). The child therefore experiences little of the fifth and final stage of the sleep cycle – REM sleep. Urinary symptoms are often the presenting complaint for children with PANDAS. A pediatric clinic-based case series reported that 7 of 12 PANDAS patients initially presented with urinary symptoms, including the new onset of nighttime bedwetting (secondary enuresis), daytime urinary frequency, and an urgency to void, without evidence of a urinary tract infection. Subsequent experience has confirmed that urinary symptoms occur frequently during recurrences, as well as at the onset of symptoms. The symptoms are occasionally related to obsessional concerns with toileting or contamination fears, but for most children, no cognitive or emotional explanation can be found