Frequency and impact of PANDAS/PANS diagnosis

Please complete the following sections for the case identified above. If the information asked below is not readily available, please leave it blank. Strict confidentiality of information will be assured.

CASE DEFINITION FOR FREQUENCY AND IMPACT OF PANDAS/PANS DIAGNOSIS

Report any child between the ages of 3 years and 18 years (up to the 18th birthday), seen in the previous month who has received* the diagnostic label of PANDAS (paediatric autoimmune neuropsychiatric disorders associated with streptococcal infection) or PANS (paediatric acute-onset neuropsychiatric syndrome).

* The diagnosis was given by any health care provider (generalist, specialist, subspecialist, allied health care provider, or complementary/alternative health care provider) or a family member.

SECTION 1 – DEMOGRAPHIC INFORMATION

1.1 Date of birth: _____ /_______

1.2 Gender: 

☐ Male ☐ Female ☐ Gender diverse

1.3 Province/territory of diagnosis: ________________________________

1.4 Pre-existing diagnoses (check all that apply):

☐ Autism ☐ Eating disorder ☐ Obsessive-compulsive disorder (OCD)

☐ Developmental disorder ☐ Behavioural disorder ☐ Attention-deficit/hyperactivity disorder

☐ Anxiety/depression ☐ Tics/Tourette syndrome ☐ None

☐ Other, specify: __________________________________________

SECTION 2 – CLINICAL PRESENTATION OF PANDAS/PANS

2.1 Date of symptom onset: ____ /_______  If not known, age of symptom onset: _____years

2.2 Pace of symptom onset:

☐ Abrupt (no symptoms to severe symptoms within 48 hours)

☐ Gradual (no symptoms to severe symptoms over a time period of greater than 48 hours)

☐ Unknown/not asked

2.3 Neuropsychiatric symptoms associated with PANDAS/PANS diagnosis (check all that apply):

Obssessive-compulsive symptoms:

Fears of contamination or illness ☐ Yes ☐ No ☐ Unknown/not asked

Fears of harming self or others ☐ Yes ☐ No ☐ Unknown/not asked

Need for order/symmetry ☐ Yes ☐ No ☐ Unknown/not asked

Taboo thoughts (sexual/aggressive) ☐ Yes ☐ No ☐ Unknown/not asked

Cleaning/washing ☐ Yes ☐ No ☐ Unknown/not asked

Checking/counting ☐ Yes ☐ No ☐ Unknown/not asked

Ordering/list making/rituals ☐ Yes ☐ No ☐ Unknown/not asked

Other, specify: __________________________________________

Abnormal movements:

Tics ☐ Yes ☐ No ☐ Unknown/not asked

Choreiform movements ☐ Yes ☐ No ☐ Unknown/not asked

Other, specify: __________________________________________
**Other neurobehavioural symptoms:**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Unknown/not asked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
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<tr>
<td>Emotional lability</td>
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<td>Hyperactivity</td>
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<tr>
<td>Depression/low mood</td>
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<tr>
<td>Irritability/agitation</td>
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<tr>
<td>Aggression</td>
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<tr>
<td>Severely oppositional behaviours</td>
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<tr>
<td>Behavioural regression</td>
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<tr>
<td>Deterioration in school performance</td>
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<tr>
<td>Sensory hypersensitivity</td>
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<tr>
<td>Hallucinations</td>
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<tr>
<td>Fine motor/handwriting deterioration</td>
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<tr>
<td>Clumsiness</td>
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<tr>
<td>Sleep disturbance</td>
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<tr>
<td>New onset enuresis</td>
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<tr>
<td>Urinary frequency</td>
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<td></td>
<td></td>
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<tr>
<td>Food refusal</td>
<td></td>
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</tr>
</tbody>
</table>

Other, specify: _________________________________________

2.4 a) Was symptom **onset** associated with:

- A microbiologically confirmed group A strep infection? [ ] Yes [ ] No [ ] Unknown
- A documented infection other than group A strep? [ ] Yes [ ] No [ ] Unknown

b) Was symptom **exacerbation** associated with:

- A microbiologically confirmed group A strep infection? [ ] Yes [ ] No [ ] Unknown [ ] Not applicable
- A documented infection other than group A strep? [ ] Yes [ ] No [ ] Unknown [ ] Not applicable

2.5 Physical examination abnormalities (check all that apply):

- Tics
- Choreiform movements
- Neurologic examination abnormalities, specify: ______________
- Other, specify: ________________________________

2.6 Who diagnosed the patient with PANDAS/PANS? (check all that apply):

- Primary care practitioner
- General paediatrician
- Family member
- Subspecialty paediatrician, specify: ________________________________
- Allied health provider (e.g., psychologist), specify: ________________________________
- Complementary/alternative health care provider (e.g., naturopath), specify: ________________________________
- Other, specify: ________________________________

**SECTION 3 – IMPACT OF SYMPTOMS**

3.1 Impact on child and family (check all that apply):

- School absences
- Decline in school achievement
- Withdrawal from social activities/friends
- Withdrawal from sports/physical activity
- New or increased intra-family stress, mental health concerns, or conflict
- Financial burden related to cost of travel, tests, or treatment
- Other, specify: ________________________________

**SECTION 4 – HEALTH UTILIZATION SINCE ONSET OF SYMPTOMS**

4.1 What services have been accessed since the onset of symptoms?

- Emergency department visit(s) [ ] Yes [ ] No [ ] Unknown
- Hospital inpatient medical admission [ ] Yes [ ] No [ ] Unknown
- Psychiatric admission [ ] Yes [ ] No [ ] Unknown
Complementary/alternative health provider  ☐ Yes  ☐ No  ☐ Unknown
Travel out of province for management  ☐ Yes  ☐ No  ☐ Unknown
Travel out of country for management  ☐ Yes  ☐ No  ☐ Unknown
Other, specify: ____________________________________________

4.2 Total number of health care visits to all service providers (as listed above) since the onset of symptoms:
☐ < 5 visits  ☐ 5–10 visits  ☐ 11–20 visits  ☐ > 20 visits  ☐ Unknown

4.3 Has the patient been referred to or been seen by any of the following specialists since the onset of symptoms? (check all that apply):
☐ General paediatrician  ☐ Psychiatrist  ☐ Neurologist
☐ Psychologist  ☐ Gastroenterologist  ☐ Rheumatologist
☐ Immunologist  ☐ Infectious disease specialist
☐ Other, specify: ____________________________  ☐ None

4.4 Total number of health care providers (as listed above) referred to and/or seen since the onset of symptoms:
☐ < 5 providers  ☐ 5–10 providers  ☐ 11–20 providers  ☐ > 20 providers  ☐ Unknown

SECTION 5 – MEDICAL EVALUATION

5.1 Testing for group A streptococcal infection (check all tests completed for this patient):
☐ Rapid strep test  ☐ Throat culture for group A strep  ☐ ASOT  ☐ Anti-DNase B
☐ Other group A strep test, specify ____________________________  ☐ None  ☐ Unknown

5.2 Other medical tests (check all tests ordered/completed):
☐ Bloodwork (i.e., any of CBC, ESR, CRP, ANA, other)  ☐ Neuroimaging (i.e., CT or MRI head)
☐ EEG  ☐ Lumbar puncture  ☐ Other, specify: ____________________________  ☐ None  ☐ Unknown

SECTION 6 – TREATMENTS/INTERVENTIONS

6.1 Treatments prescribed/received (check all that apply):

Antibiotics/treatment for group A streptococcal (GAS) infection:
☐ Antibiotic treatment course for GAS  ☐ Antibiotic prophylaxis for GAS
☐ Antibiotic eradication of GAS carriage  ☐ Tonsillectomy
☐ Other, specify: ____________________________  ☐ Unknown

OCD/tic treatments:
☐ Psychotropic medication (i.e., SSRIs, antipsychotics, clonidine)
☐ Psychological treatments (i.e., cognitive behavioural therapy, habit reversal therapy)
☐ Other, specify: ____________________________  ☐ Unknown

Anti-inflammatory/immune modulation treatments:
☐ NSAIDs  ☐ Corticosteroids  ☐ Rituximab
☐ IVIG  ☐ Plasma exchange  ☐ Unknown
☐ Other treatment, specify: ____________________________________________

SECTION 7 – CERTAINTY OF DIAGNOSIS

7.1 How certain are you of the diagnosis of PANDAS/PANS in this patient?
☐ Ruled-out  ☐ Unlikely  ☐ Uncertain  ☐ Likely  ☐ Certain
If ruled out, list alternate diagnosis: ____________________________________________

7.2 How strongly does the family believe the diagnosis is PANDAS/PANS?
☐ Do not believe  ☐ Uncertain  ☐ Somewhat believe  ☐ Strongly believe  ☐ Certain
SECTION 8 – PROVIDER INFORMATION

Specialty:
- General paediatrician (providing primary care)
- General paediatrician (providing consultative care)
- Paediatric neurologist
- Paediatric infectious disease specialist
- Paediatric rheumatologist
- Psychiatrist
- Other, specify: _____________________________

Practice setting:
- Inpatient hospital
- Emergency department
- Outpatient clinic
- Private office

☐ I agree to be contacted by the CPSP for further information on this questionnaire.
☐ I do not wish to be contacted by the CPSP for further information on this questionnaire.

SECTION 9 – REPORTING PHYSICIAN

First name ___________________________ Surname ________________________________
Address ________________________________
City ___________________ Province _______________ Postal code _________
Telephone number __________________________ Fax number __________________________
E-mail ________________________________ Date completed __________________________

Thank you for completing this form.

(PANDAS/PANS 11/2019)