

# ACQUIRED DEMYELINATING SYNDROMES OF THE CENTRAL NERVOUS SYSTEM (ADS)

## CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

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### REPORTING INFORMATION

(To be completed by the CPSP Senior Coordinator)

Report number: \_\_\_\_\_

Month of reporting: \_\_\_\_\_

Province: \_\_\_\_\_

Today's date: \_\_\_\_\_

**Please complete the following sections for the case identified above.  
Confidentiality of information will be assured.**

### CASE DEFINITION FOR ACQUIRED DEMYELINATING SYNDROMES OF THE CENTRAL NERVOUS SYSTEM

Report any child < 18 years with one of the following syndromes:

- Acute loss of vision (**optic neuritis**): decreased visual acuity of one or both eyes, typically maximal over a period of days, often associated with pain. CT/MRI may show swelling and abnormal signal of optic nerves.
- Spinal cord dysfunction (**transverse myelitis**): weakness and/or numbness of both legs +/- arms, often associated with bladder retention with maximal deficits 4 to 21 days after symptom onset. MRI may demonstrate swelling and/or abnormal signal in the spinal cord.
- Acute neurological deficits: **acute neurological dysfunction** (i.e., weakness, numbness/tingling, loss of balance, impaired eye movements, double vision, poor coordination) maximal within 4 to 21 days after onset associated with MRI evidence of at least one area of abnormal white matter signal of the brain or spinal cord. Level of consciousness should be normal, and fever or neck stiffness absent.
- Acute disseminated encephalomyelitis (**ADEM**): acute neurological deficits (weakness, numbness, loss of balance) associated with at least two of: (1) viral prodromal illness within the last 28 days; (2) fever, (3) stiff neck, (4) headache, (5) altered level of consciousness or behavior, or (6) seizures. MRI shows multiple areas of abnormal signal in the white matter.

#### Exclusion criteria

- Demyelination of the peripheral nervous system (i.e., Guillain-Barré syndrome, chronic inflammatory demyelinating polyneuropathy)
- Leukodystrophies (i.e., metachromatic leukodystrophy, adrenoleukodystrophy, etc.) or mitochondrial disease
- Active CNS infection (i.e., bacterial meningitis, herpes simplex encephalitis, Lyme disease, HIV, HTLV-1, West Nile virus)
- Radiation/chemotherapy associated white matter damage

## SECTION 1 – DEMOGRAPHIC INFORMATION

1.1 Date of birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
                                    DD   MM   YYYY

1.2 Sex: Male \_\_\_ Female \_\_\_

1.3 Current residence: Province: \_\_\_\_\_ Rural \_\_\_ Urban \_\_\_

1.4 Was the child born in Canada? Yes \_\_\_ No \_\_\_

If no, specify country of birth: \_\_\_\_\_

Age at immigration to Canada: \_\_\_\_\_ (years)

1.5 Country of birth — Mother: \_\_\_\_\_ Father: \_\_\_\_\_

1.6 Parental ancestry/heritage (i.e., to what ethnic group does the family view itself as belonging)?

(For example, a woman whose ancestors are from India, but who was herself born in the U.K. would list the U.K. as country of birth, but ethnicity would be East Indian.)

Maternal: \_\_\_\_\_ Paternal: \_\_\_\_\_

**SECTION 2 – RELEVANT FAMILY MEDICAL HISTORY**

2.1 Patient history of:

Multiple sclerosis Yes \_\_\_ No \_\_\_ Unknown \_\_\_  
 Juvenile diabetes mellitus Yes \_\_\_ No \_\_\_ Unknown \_\_\_  
 Systemic lupus Yes \_\_\_ No \_\_\_ Unknown \_\_\_  
 Thyroiditis Yes \_\_\_ No \_\_\_ Unknown \_\_\_  
 Other: Yes \_\_\_ No \_\_\_ Unknown \_\_\_

2.2 Family history of:

Multiple sclerosis Yes \_\_\_ No \_\_\_ Unknown \_\_\_ Relationship to patient \_\_\_\_\_  
 Juvenile diabetes mellitus Yes \_\_\_ No \_\_\_ Unknown \_\_\_ Relationship to patient \_\_\_\_\_  
 Systemic lupus Yes \_\_\_ No \_\_\_ Unknown \_\_\_ Relationship to patient \_\_\_\_\_  
 Thyroiditis Yes \_\_\_ No \_\_\_ Unknown \_\_\_ Relationship to patient \_\_\_\_\_  
 Other: Yes \_\_\_ No \_\_\_ Unknown \_\_\_ Relationship to patient \_\_\_\_\_

**SECTION 3 – CLINICAL FEATURES**

3.1 Date of demyelinating event: \_\_\_ / \_\_\_ / \_\_\_  
DD MM YYYY

3.2 Demyelinating signs and symptoms (check all that apply)

<input type="checkbox"/> Bilateral visual loss (involvement of both eyes within 30 days of each other)	<input type="checkbox"/> Bladder retention +/- bowel dysfunction*
<input type="checkbox"/> Visual loss (one eye only)	<input type="checkbox"/> Loss of balance (gait ataxia)
<input type="checkbox"/> Double vision	<input type="checkbox"/> Impaired co-ordination of arms/legs (limb ataxia)
<input type="checkbox"/> Facial pain and numbness	<input type="checkbox"/> Confusion or impaired alertness
<input type="checkbox"/> Loss of sensation (one side of face only without facial pain)	<input type="checkbox"/> Fever
<input type="checkbox"/> Weakness (one side of face only)	<input type="checkbox"/> Neck Stiffness
<input type="checkbox"/> Loss of sensation (one sided, involving face, arm and leg)	<input type="checkbox"/> Headache
<input type="checkbox"/> Weakness (arm and leg +/- face, all on same side of body)*	<input type="checkbox"/> Seizures
<input type="checkbox"/> Loss of sensation (both legs and/or both arms at the same time)*	<input type="checkbox"/> Dizziness +/- nausea
<input type="checkbox"/> Weakness (both legs and/or both arms)*	<input type="checkbox"/> Fatigue
	<input type="checkbox"/> Other (specify): _____
	<input type="checkbox"/> Unknown
	<input type="checkbox"/> Not recorded

\*All of these symptoms/signs are associated with transverse myelitis, but are recorded separately for clarity.

3.3 Was the child diagnosed with acute disseminated encephalomyelitis (ADEM)?

Yes \_\_\_ No \_\_\_ Unknown \_\_\_

3.4 MRI performed: Yes \_\_\_ No \_\_\_ Unknown \_\_\_

3.5 Abnormal white matter on MRI: Yes \_\_\_ No \_\_\_

3.6 CSF- positive for oligoclonal bands: Yes \_\_\_ No \_\_\_ Not done \_\_\_ Unknown \_\_\_

3.7 Did the child require treatment? Yes \_\_\_ No \_\_\_

If yes, specify:

IV solumedrol \_\_\_ Dose \_\_\_\_\_ Number of days \_\_\_\_\_

Oral Prednisone \_\_\_ Dose \_\_\_\_\_ Number of days \_\_\_\_\_

Intravenous Immune Globulin \_\_\_ Dose \_\_\_\_\_ Number of days \_\_\_\_\_

Other: \_\_\_\_\_

**SECTION 3 – CLINICAL FEATURES (cont'd)**

3.8 Was the demyelinating episode preceded by an infection within one month? Yes \_\_\_ No \_\_\_

If yes, was an organism identified (specify) \_\_\_\_\_

3.9 Did the child receive a vaccination within one month prior to the demyelinating episode?

If yes, specify vaccine: \_\_\_\_\_ Date given (month/year): \_\_\_\_ / \_\_\_\_  
MM YYYY

3.10 Was this demyelinating episode the child's FIRST one? Yes \_\_\_ No \_\_\_

3.11 If this was the FIRST episode:

Did you discuss the possibility of recurrent demyelination (i.e., multiple sclerosis) with the child/family?

Yes \_\_\_ No \_\_\_

3.12 If this was NOT THE FIRST demyelinating episode:

- How many other demyelinating episodes has the child experienced? \_\_\_\_\_
- Did the other episodes of demyelination occur within one month \_\_\_\_, six months \_\_\_\_ or greater than six months \_\_\_\_ from the current demyelinating episode?
- Were the other demyelinating episode(s) exactly the same clinical symptoms as the current episode (i.e., visual loss in the same eye on two occasions)?  
Yes \_\_\_ No, the symptoms have been different in the other demyelinating episode(s) \_\_\_

**SECTION 4 – REPORTING PHYSICIAN**

First name \_\_\_\_\_ Surname \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ Province \_\_\_\_\_ Postal code \_\_\_\_\_

Telephone number \_\_\_\_\_ Fax number \_\_\_\_\_

E-mail \_\_\_\_\_ Date completed \_\_\_\_\_

**Thank you for completing this form.**