ACQUIRED DEMYELINATING SYNDROMES OF THE CENTRAL NERVOUS SYSTEM (ADS)

CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

2305 St. Laurent Blvd.
Ottawa ON K1G 4J8
Tel: (613) 526-9397, ext. 239
Fax: (613) 526-3332
E-mail: cpsp@cps.ca
Web site: www.cps.ca/english/cpsp

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: ___ / ___ / ___ 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: _____ /_____ /_______

3.2 Demyelinating signs and symptoms (check all that apply)
- ___ Bilateral visual loss (involvement of both eyes within 30 days of each other)
- ___ Visual loss (one eye only)
- ___ Double vision
- ___ Facial pain and numbness
- ___ Loss of sensation (one side of face only without facial pain)
- ___ Weakness (one side of face only)
- ___ Loss of sensation (one sided, involving face, arm and leg)
- ___ Weakness (arm and leg +/- face, all on same side of body)*
- ___ Loss of sensation (both legs and/or both arms at the same time)*
- ___ Weakness (both legs and/or both arms)*
- ___ Bladder retention +/- bowel dysfunction*
- ___ Loss of balance (gait ataxia)
- ___ Impaired co-ordination of arms/legs (limb ataxia)
- ___ Confusion or impaired alertness
- ___ Fever
- ___ Neck Stiffness
- ___ Headache
- ___ Seizures
- ___ Dizziness +/- nausea
- ___ Fatigue
- ___ Other (specify): _________________________
- ___ Unknown
- ___ 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 with 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): _____ /_______

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.

(ADS 2004-04)