Paediatric myasthenia (PM)

CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM
2305 St. Laurent Blvd.
Ottawa, ON K1G 4J8
Tel: 613-526-9397, ext. 239
Fax: 613-526-3332
cpsp@cps.ca
www.cps.ca/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.
Strict confidentiality of information will be assured.

CASE DEFINITION FOR PAEDIATRIC MYASTHENIA

Report any child less than 18 years of age with at least one of the following clinical features:

- fluctuating ptosis (may be unilateral or bilateral) and/or
- fluctuating extraocular muscle weakness (unilateral or bilateral) and/or
- history of skeletal muscle weakness or fatigue

AND any of the following supportive tests:

- Tensilon™ test (edrophonium) (or other acetylcholinesterase inhibitor) demonstrating reversal of weakness
- elevated acetylcholine receptor or MuSK (muscle specific kinase) antibody levels
- abnormal nerve conduction studies (demonstrating defect in neuromuscular junction transmission) or single fiber EMG

Exclusion criteria

- Underlying primary muscle disease
- Underlying metabolic disease
- Transient neonatal myasthenia

Month first seen _____

SECTION 1 – DEMOGRAPHIC INFORMATION

1.1 Date of birth: _____ /_____ /_____ (DD MM YYYY) 1.2 Sex: Male ___ Female ___

1.3 Province/Territory of residence: _____ 1.4 Born in Canada? Yes ___ No ___

1.5 Ethnicity - mother

First Nations ___ Innu ___ Inuit ___ Métis ___ Chinese ___ Japanese ___ Other Oriental ___
East Indian ___ Black ___ Caucasian ___ Latin American ___ Middle Eastern ___
Other (specify) _____ Unknown ___

1.6 Ethnicity - father

First Nations ___ Innu ___ Inuit ___ Métis ___ Chinese ___ Japanese ___ Other Oriental ___
East Indian ___ Black ___ Caucasian ___ Latin American ___ Middle Eastern ___
Other (specify) _____ Unknown ___

SECTION 2 – FAMILY MEDICAL HISTORY (parents and siblings)

2.1 Relative with autoimmune disease? Yes ___ No ___ Unknown ___

If yes, specify relationship: _____

2.2 Relative with myasthenic syndrome? Yes ___ No ___ Unknown ___

If yes, specify relationship: _____

SECTION 3 – CLINICAL PRESENTATION

3.1 Age of symptom onset: ___ at birth _____ years / months ___ unknown

3.2 Age at presentation: ___ at birth _____ years / months ___ unknown

3.3 At diagnosis:

3.3.1 Presenting symptoms/findings (check all that apply):	Yes	No	Unknown
• Diplopia			
• Ptosis			
• Swallowing / chewing difficulties			
• Hypotonia			
• Fatigue			
• Respiratory difficulties			
• Delayed development			
• Other (specify):			

3.3.2 Physical examination findings (check all that apply):	Yes	No	Unknown
• Unilateral ptosis at rest or with sustained upgaze			
• Bilateral ptosis at rest or with sustained upgaze			
• Extra-ocular movement abnormalities			
• Facial weakness			
• Hypophonia / voice alteration			
• Articulation difficulties			
• Neck flexor weakness			
• Fatigable shoulder girdle weakness			
• Fatigable hip weakness			
• Respiratory distress			
• Respiratory failure			
• Other (specify):			

3.4 Did ocular features precede bulbar (face/throat) or limb symptoms? Yes ___ No ___ Unknown ___

If yes, by how many months? _____

SECTION 4 – LABORATORY INVESTIGATIONS

4.1 Please check all that apply:	Not done	Normal	Abnormal	Results (units)
• Acetylcholine receptor antibody titers*	___	___	___	_____
• MuSK (muscle specific kinase) antibodies*	___	___	___	_____
• Tensilon™ test (edrophonium)	___	___	___	_____
• Thymus imaging (CT/MRI chest)	___	___	___	_____
• Nerve conduction studies (repetitive stimulation)	___	___	___	_____
• Single fiber EMG	___	___	___	_____
• Thyroid function tests*	___	___	___	_____

* Please indicate units

SECTION 5 – OTHER RELEVANT MEDICAL HISTORY

5.1 Please specify concurrent medical conditions/concerns:

_____

_____

SECTION 6 – INITIAL TREATMENTS

6.1 Please check all that apply. If multiple therapies, specify sequence of treatment.

	Dose	Duration	Sequence of treatment	Current treatment		Improvement	
				Yes	No	Yes	No
Pyridostigmine bromide							
Prednisone							
IVIG							
Plasmapheresis							
Other (specify):							
Thymectomy: Yes ___ No ___							
If yes, type of surgery and pathological result: _____							

SECTION 7 – OUTCOME

7.1 Indicate age at last follow-up: _____ months / years

7.2 Outcome at last follow-up

7.2.1 Hospital stay: Total number of days _____ Days in intensive care units _____ Still in hospital ___

7.2.2 Home ____

7.2.3 Patient condition:

- Fully recovered/remission ____
- Partially recovered ____
- Not recovered/non-responder ____

7.2.4 Deceased ____

7.2.5 Unknown ____

7.2.6 Other, specify: _____

___ **I agree to be contacted by the research team for further information.**

___ **I do not wish to be contacted by the research team for further information.**

(OVER)

SECTION 8 – REPORTING PHYSICIAN

First name_____ Surname_____

Address_____

City_____ Province_____ Postal code_____

Telephone number_____ Fax number_____

E-mail_____ Date completed_____

Thank you for completing this form.