EudraCT number: 2016-000997-39 Confidential once completed

## **ECUSTEC Central Nervous System (CNS) Assessment Worksheet**

	Hospital name:							
	Trial number:							
	Date of Birth:							
Please complete this worksheet for the day 60 assessment visit if the patient experienced CNS features during the acute disease (STEC HUS). Once completed, the paediatric neurologist responsible will use the information on the worksheet as Source Data from which to assign a CNS score for the ECUSTEC trial.  ECUSTEC CNS Assessment*  Level of consciousness / alertness  Result Normal DAbnormal Not possible D								
Result  Details if abnorma			AUHUHHII		I NOT POSSIBLE			
Cranial nerves Result	Normal [	7	Abnormal		Not possible			
Details if abnorma		<b>)</b>						
Tone								
Result	Normal [	<b>¬</b>	Abnormal		Not possible	П		
Details if abnorma		<u>-</u>	Ashermal		1100 90331016			
Abnormalities of movement								
Result	No abnormal movements		Abnormal movements	s 🗆	Not possible			
Details of abnorma								
Abnormalities of I	paiance/gait							

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Result	Normal balance/gait  □	Abnormal balance/gait □	Not possible					
Details of abnormal ba		Dalance/gait 🗀						
Details of abilionnial ba	iance, gait							
Madmaa								
Weakness	No. and annual T	Maria and a second	Not constitute					
Result	No weakness	Weakness present  ☐	Not possible					
Details of weakness								
			$\langle X \rangle Y$					
Neuropathy			7					
Result	No neuropathy □	Evidence of neuropathy	Not possible □					
Details of neuropathy								
New epileptic seizures	(since onset STEC HUS)							
Result	No new seizures  ☐	New seizures	Not possible					
Details of seizures								
Summary								
Does this child have a normal neurological examination?								
Yes								
If no, in your opinion (from parental reports and any available pre-morbid records) has this occurred since onset of STEC HUS?								
Yes $\square$	No 🗆	Unable to comment						

**ECUSTEC Source Data:** this worksheet is to be filed in the ECUSTEC Site File and a copy should be added to the patient medical notes.

## \*Examination should include the following:

- Level of consciousness / alertness
- Abnormalities of cranial nerves
  - Single
  - o Multiple
- Abnormalities of tone
  - Hypotonia
    - Axial
    - Post-axial
  - Hypertonia
    - Spastic or dystonic
    - Generalised or focal
    - Arms v legs
    - Trunk v limbs
    - Head lag/drop
- Abnormalities of movement
  - Tremor
    - Location
    - Rest v Action v Postural
    - Symmetrical
  - Myoclonus
  - Choreoathetosis
    - Location
    - Frequency
- Abnormalities of balance/gait
  - Cerebellar ataxia
    - Upper limb dysmetria
    - Associated conjugate nystagmus
    - Associated tremor
  - Sensory ataxia (peripheral neuropathy)
  - Spastic v waddling v ataxic gait
- Weakness
  - Flaccid v Spastic
  - o Hemiplegia, Monoplegia, Diplegia
  - Proximal v distal
  - Mobility wheelchair; assisted walking; independently mobile (age appropriate)
- Neuropathy
  - Mononeuropathy
  - Mononeuritis multiplex
- New epileptic seizures (since onset of disease)
  - Focal v Generalised
  - Focal semiology; secondary generalisation
  - Generalised GTCS, absence seizures
  - Frequency of seizure types
  - Response to medication