EudraCT number: 2016-000997-39 Confidential once completed

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

Н	ospital name:							
Tr	ial number:							
Da	ate of Birth:							
Diagon complete this would be at four the play CO assessment with lift the matient arms it would CALC.								
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 <u>Source Data</u> from which to assign a CNS								
score for the ECUSTEC trial.								
ECUSTEC CNS Assessment*								
Level of consciousnes	ss / alertness			4				
Result	Normal		Abnormal		Not possible			
Details if abnormal					-			
			1 \ )	·				
Cranial nerves								
Result	Normal		Abnormal		Not possible			
Details if abnormal								
	$\wedge$							
Tone								
Result	Normal	П	Abnormal		Not possible			
Details if abnormal	Norman		7101111111		140t possible			
Details if abriormal								
Abnormalities of movement								
Result	No abnormal		Abnormal		Not possible	$\neg$		
nesuit	movements	П	movements		Not possible			
Details of abnormal m			movements	, <b>ப</b>				
Details of abhormal fi	io vemento							

Abnormalities of balance/gait

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Result	Normal balance/gait  □	Abnormal balance/gait □	Not possible					
Details of abnormal balance/gait								
Details of abilionnial ba	ialice/gait							
Weakness								
Result	No weakness	Weakness present □	Not possible					
Details of weakness								
			Y					
Neuropathy		<u> </u>	M					
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 🗆	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