Creutzfeldt-Jakob Disease Worksheet

Please complete the Basic Case Form to capture all of the profile and basic data for ALL Merlin cases.

Basic Case Form: http://www.doh.state.fl.us/Disease_ctrl/epi/surv/Basic_Case_Investigation_Form.pdf

CURRENT STATUS

Date of Death: _____ **or Last Date Known Alive:** _____

Family Contact: _____ **Relationship:** _____ **Phone:** _____

ATTENDING/PRIMARY PHYSICIAN

Name : _____ **Phone:** _____

Address: _____ **Fax:** _____

City: _____ **State:** _____ **Zip:** _____

Speciality: _____

HISTORY AND PHYSICAL FINDINGS

Onset of initial symptom: _____ **What was the duration of illness from onset to death in months?** _____ **or** ☐ **NA**

Patient's Clinical Data	**Yes**	**No**	**Unk**	**Date***
Did the patient have akinetic mutism?	☐	☐	☐	_____
Did the patient have poor coordination/ataxia?	☐	☐	☐	_____
Did the patient have dementia?	☐	☐	☐	_____
If the patient had dementia was it characterized as rapidly progressing?	☐	☐	☐	_____
Did the patient have persistent painful sensory symptom/s? (frank pain and/or dysesthesia)	☐	☐	☐	_____
Did the patient have visual signs?	☐	☐	☐	_____
Did the patient have myoclonus?	☐	☐	☐	_____
Did the patient have chorea?	☐	☐	☐	_____
Did the patient have dystonia?	☐	☐	☐	_____
Did the patient have progressive neuropsychiatric disorder?	☐	☐	☐	_____
Did the patient have early psychiatric symptom/s? (anxiety, apathy, delusions, depression and/or withdrawal)	☐	☐	☐	_____
Did the patient have the psychiatric symptom/s at illness onset?	☐	☐	☐	_____
Did the patient have an EEG? (attach copy of report)	☐	☐	☐	_____
If yes, did the report indicate a diagnosis of CJD?	☐	☐	☐	_____
Did the patient have a MRI scan? (attach copy of report)	☐	☐	☐	_____
Did the patient have a 14-3-3 CSF protein analysis?	☐	☐	☐	_____
If yes, were the results ☐ **Positive** ☐ **Negative** ☐ **Ambiguous** ☐ **Unknown**				
Did the routine investigation of the patient indicate an alternative, non CJD diagnosis?	☐	☐	☐	_____
Past Medial and Social History				
Is there a history of receipt of human pituitary growth hormone, a dura mater or corneal graft?	☐	☐	☐	
If yes, please specify: _____				
Is there a history of receiving a blood transfusion? (If yes, last date: _____**)**	☐	☐	☐	
Is there a history of donating blood or blood products?	☐	☐	☐	
Is there a history of neurosurgery prior to onset of symptoms?	☐	☐	☐	
If yes, please specify date and type of surgery: _____				
Is there a history of CJD in a first-degree relative? (parent, sibling, child)	☐	☐	☐	
If yes, who and at what age: _____				

	Yes	No	Unk
Is there a history of living in a foreign country for >3 months since 1985?	○	○	○
If yes, name country and dates: _____			

Neuropathology Information

Is a neuropathology report available on this patient?	○	○	○
Was a brain biopsy performed on this patient?	○	○	○
Was a brain autopsy performed on this patient?	○	○	○
If a biopsy or an autopsy was performed, was brain tissue sent to the National Prion Disease Pathology Surveillance Center at Case Western Reserve Univerity, Cleveland Ohio?	○	○	○
Is the pathology report attached to this case report?	○	○	○

* Date should be date of onset or date test conducted. If exact onset date is unknown, month and year is acceptable.

The following reports should be attached to the worksheet if available:
Death Certificate **Brain Pathology** **14-3-3 SCSF Protein** **EEG** **MRI**

Additional details:

Entered by _____ **on** _____