FORM FOR INVESTIGATING
CREUTZFELDT-JAKOB DISEASE CASES AGED <55 YEARS

Form Approved
OMB 0920-009

CDC No__ __ __ __ __ __ __

I. General Information

Patient's code number: __ __ __ __ __ __ __ Date form filled out: _ _/ _ _/_ _ _ _ (mm/dd/yyyy)

State of death occurrence: _____ County of death occurrence: _____

State of residence: _____ County of residence: _____

Date of birth: _ _/_ _/_ _ _ _ (mm/dd/yyyy) Age at death: __ __ years Sex: 1 Male 2 Female

Ethnicity: 1 Hispanic or Latino 2 Not Hispanic or Latino

Race (mark one or more): 1 White 2 Black or African American 3 Asian

4 Native Hawaiian/Other pacific islander 5 American Indian/Alaska Native 6 Unknown

Month and year of initial symptoms:_ _/_ _ _ _ (mm/yyyy) Date of death: _ _/_ _/_ _ _ _ (mm/dd/yyyy)

II. Patient's Clinical Data

	Yes	No	Unknown
Did the patient have a progressive neuropsychiatric disorder?	1	2	9
Did the patient have early psychiatric symptom/s (anxiety, apathy, delusions, depression, and/or withdrawal)?	1	2	9
Did the patient have the psychiatric symptom/s at illness onset?	1	2	9
Did the patient have persistent painful sensory symptom/s (frank pain and/or dysesthesia)?	1	2	9
Did the patient have dementia?	1	2	9
Did the patient have poor coordination/ataxia?	1	2	9
Did the patient have myoclonus?	1	2	9
Did the patient have chorea?	1	2	9
Did the patient have dystonia?	1	2	9
Did the patient have hyperreflexia?	1	2	9
Did the patient have visual signs?	1	2	9
Did the patient have dementia as well as development at least 4 months after illness onset of at least two of the following five neurologic signs: poor coordination, myoclonus, chorea, hyperreflexia, or visual signs?	1	2	9
Was the duration of illness over 6 months?	1	2	9
Is there a history of receipt of human pituitary growth hormone, a dura mater graft, or a corneal graft?	1	2	9
If yes, please specify:_____			
Is there a history of CJD in a first degree relative?	1	2	9
Is there a prion protein gene mutation in the patient?	1	2	9

	Yes	No	Unknown
Did a radiologist or an attending physician report that the patient's EEG was indicative of a CJD diagnosis?	1	2	9
According to the radiologist or an attending physician, did the MRI scan show bilateral pulvinar high signal?	1	2	9
Did routine investigation of the patient indicate an alternative, non-CJD diagnosis?	1	2	9

III. Neuropathology Information

Is a neuropathology report available on this patient?	1	2	9
Was a brain biopsy performed on this patient?	1	2	9
Was a brain autopsy performed on this patient?	1	2	9
If a biopsy or an autopsy was performed, was brain tissue sent to the National Prion Disease Pathology Surveillance Center at Case Western Reserve University, Cleveland, Ohio?	1	2	9
According to the pathologist's report, was the neuropathology indicative of a CJD diagnosis?	1	2	9
Are there numerous widespread kuru-type amyloid plaques surrounded by vacuoles (florid plaques) in both the cerebellum and cerebrum?	1	2	9
Is there spongiform change and extensive prion protein deposition shown by immunohistochemistry throughout the cerebellum and cerebrum?	1	2	9

IV. Case Assessment

Does the patient have clinical findings similar to that of the variant CJD?	1	2	9
Does the patient have neuropathologic findings confirming a variant CJD diagnosis?	1	2	9

IMPORTANT: Please attach the patient's neuropathology report, if available.

Comments: