

**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: