

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

I. General Information

Patient's name _____ Date form filled out: __/__/____ (mm/dd/yyyy)

Date of birth: __/__/____ (mm/dd/yyyy) Country of birth: _____

State of residence: _____ County of residence: _____

How long has the patient lived in the US? _____

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/year of initial symptoms: __/____ (mm/yyyy) Date of death: __/__/____ (mm/dd/yyyy)

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

Age at death: __ years

Where is the patient currently located? _____ (current address)

What is the patient's permanent address (if different from current address)? _____

What is the phone number at the current address? ____-____-_____ Permanent address? ____-____-_____

At what hospitals was the patient seen? _____

Does the patient have a known history of foreign travel? 1: Yes 2: No 9: Unknown

If yes, where? _____

Does the patient have a history of hunting or eating wild game? 1: Yes 2: No 9: Unknown

If yes, in what state? _____

Does the patient have a family history of CJD or early onset dementia? 1: Yes 2: No 9: Unknown



If yes, please describe: _____

| 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? If yes, please specify: _____ | 1 | 2 | 9 |
| Is there a history of CJD in a first degree relative? | 1 | 2 | 9 |



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|---|---|---|---|
| Is there a prion protein gene mutation in the patient? | 1 | 2 | 9 |
| 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 |
| Does the patient have clinical findings similar to that of the variant CJD? | 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 neuropathy 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 |
| Does the patient have neuropathologic findings confirming a variant CJD diagnosis? | 1 | 2 | 9 |





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

Name of Neurologist _____

Phone number _ _ - _ - _ _ _

Name of Attending Physician _____

Phone number _ _ - _ - _ _ _

Name of other Physician _____

Phone number _ _ - _ - _ _ _

Comments:

Form completed by: _____



We Protect Lives.