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 Ma	ile	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 Asi	ian	
4 Native Hawaiian/Other pacific islander 5 American Indian/Alaska Native	6 Un	known	
Month and year of initial symptoms:/ (mm/yyyy) Date of death	h:/_	_/	_ (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
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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

Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0009).

CD	C No_	
Yes	No	Unknown

	Yes	No	Unknown		
Did a radiologist or an attending physician report that	1	2	9		
the patient's EEG was indicative of a CJD diagnosis?			9		
According to the radiologist or an attending physician, did the MRI scan show bilateral pulvinar high signal?		2	9		
Did routine investigation of the patient indicate an alternative, non-CJD diagnosis?		2	9		
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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,	1	2	0		
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: