State of California—Health and Human Services Agency

California Department of Public Health
Center for Infectious Diseases
Division of Communicable Disease Control
Infectious Diseases Branch
Surveillance and Statistics Section
MS 7306, P.O. Box 997377
Sacramento, CA 95899-7377

Local ID Number _____

(*Please use the same ID Number on the preliminary and final reports to allow linkage to the same case.)*

Report Status (check one)

☐Preliminary ☐Final

CREUTZFELDT-JAKOB DISEASE CASE REPORT

PATIENT INFORMATION

Last Name	*First Name*	*Middle Name*	*Suffix*

Social Security Number (9 digits)	*DOB (mm/dd/yyyy)*	*Age*	☐*Years* ☐*Months* ☐*Days*

Address Number & Street - Residence	*Apartment/Unit Number*

City/Town	*State*	*Zip Code*

Census Tract	*County of Residence*	*Country of Residence*

Country of Birth	*If not U.S. Born - Date of Arrival in U.S. (mm/dd/yyyy)*

Home Telephone	*Cellular Phone/Pager*	*Work/School Telephone*

E-mail Address	*Other Electronic Contact Information*

Work/School Location	*Work/School Contact*

Gender
☐Male ☐Female ☐Other: _____

Pregnant? ☐Yes ☐No ☐Unk	*If Yes, Est. Delivery Date (mm/dd/yyyy)*

Medical Record Number	*Patient's Parent/Guardian Name*

Occupation Setting (see list on page 7)	*Other Describe/Specify*

Occupation (see list on page 7)	*Other Describe/Specify*

Primary Language
☐English
☐Spanish
☐Other:_____

Ethnicity (check one)
☐Hispanic/Latino
☐Non-Hispanic/Non-Latino
☐Unk

*Race**
(check all that apply, race descriptions on page 7)
☐African-American/Black
☐American Indian or Alaska Native
☐Asian *(check all that apply)*
- ☐Asian Indian ☐Japanese
- ☐Cambodian ☐Korean
- ☐Chinese ☐Laotian
- ☐Filipino ☐Thai
- ☐Hmong ☐Vietnamese
- ☐Other:_____

☐Pacific Islander *(check all that apply)*
- ☐Native Hawaiian ☐Samoan
- ☐Guamanian
- ☐Other:_____

☐White
☐Other:_____
☐Unk

*Comment: self-identity or self-reporting
The response to this item should be based on the patient's self-identity or self-reporting. Therefore, patients should be offered the option of selecting more than one racial designation.

CLINICAL INFORMATION

Physician Name - Last Name	*First Name*	*Telephone Number*

First three letters of patient's last name: | | | |

CLINICAL INFORMATION

RESIDENCE INFORMATION

Patient's Residence at Time of Diagnosis	*City*	*State*	*State in which Patient is Receiving Care*
Where is patient currently located? (e.g., facility name, family member living with, etc.)		*Known Date at This Location (mm/dd/yyyy)*	

DIAGNOSIS INFORMATION

Onset Date (mm/dd/yyyy)	*Date of CJD Diagnosis (mm/dd/yyyy)*	
Name of Hospital where CJD Diagnosis was Made	*Location*	
Diagnosing Physician's Name	*Telephone Number*	
Was the patient seen by a neurologist? ☐Yes ☐No ☐Unk	*If Yes, was diagnosis of CJD made by a neurologist?* ☐Yes ☐No ☐Unk	
If Yes, Neurologist's Name	*Address*	*Telephone Number*
If No, Specialty of Diagnosing Physician		

HOSPITALIZATION

Was patient hospitalized? ☐Yes ☐No ☐Unk	*If there were any ER or hospital stays related to this illness, specify details below.*

HOSPITALIZATION - DETAILS

Hospital Name 1	*Street Address*			*Admission Date (mm/dd/yyyy)*	
	City			*Discharge / Transfer Date (mm/dd/yyyy)*	
	State	*Zip Code*	*Telephone Number*	*Medical Record Number*	*Discharge Diagnosis*
Hospital Name 2	*Street Address*			*Admission Date (mm/dd/yyyy)*	
	City			*Discharge / Transfer Date (mm/dd/yyyy)*	
	State	*Zip Code*	*Telephone Number*	*Medical Record Number*	*Discharge Diagnosis*

OUTCOME

Outcome? ☐Survived ☐Died ☐Unk	*If Survived,* Survived as of _____(mm/dd/yyyy)	*Date of Death (mm/dd/yyyy)*
If Died, is CJD listed as a cause of death on the death certificate? ☐Yes ☐No ☐Unk	*If No, what was the cause of death?*	

First three letters of patient's last name: | | | |

LABORATORY INFORMATION

LABORATORY RESULTS SUMMARY

EEG performed? ☐Yes ☐No ☐Unk	*If Yes, specify results*		
MRI performed? ☐Yes ☐No ☐Unk	*If Yes, specify results*		
CSF tests? ☐Yes ☐No ☐Unk	*If Yes, specify below*		
	CSF Lab Report # 1 Date (mm/dd/yyyy)	*Was blood found in the sample?* ☐Yes ☐No ☐Unk	*CSF Results #1* 14-3-3 protein: ☐Positive ☐Negative ☐Ambiguous Tau protein: ☐Positive ☐Negative
	CSF Lab Report # 2 Date (mm/dd/yyyy)	*Was blood found in the sample?* ☐Yes ☐No ☐Unk	*CSF Results #2* 14-3-3 protein: ☐Positive ☐Negative ☐Ambiguous Tau protein: ☐Positive ☐Negative
	CSF specimens sent to the National Prion Disease Pathology Surveillance Center (NPDPSC)? ☐Yes ☐No ☐Unk		*If No, which laboratory?*
Brain biopsy performed? ☐Yes ☐No ☐Unk	*If Yes, specify below*		
	Hospital where Biopsy Performed		*Date of Biopsy (mm/dd/yyyy)*
	Specimens sent to NPDPSC? ☐Yes ☐No ☐Unk	*Western Blot* ☐Abnormal prion protein present ☐Abnormal prion protein NOT present	*Immunohistochemistry* ☐Positive ☐Negative
Autopsy performed? ☐Yes ☐No ☐Unk	*If Yes, specify below*		
	Hospital where Autopsy Performed	*Date of Autopsy (mm/dd/yyyy)*	*Autopsy Physician Name*
	Specimens sent to NPDPSC? ☐Yes ☐No ☐Unk	*Western Blot* ☐Abnormal prion protein present ☐Abnormal prion protein NOT present	*Immunohistochemistry* ☐Positive ☐Negative
Other Tests:			

EPIDEMIOLOGIC INFORMATION

EXPOSURES / RISK FACTORS

DID THE PATIENT UNDERGO ANY OF THE FOLLOWING PROCEDURES?

Procedure	Yes	No	Unk	If Yes, Specify as Noted	Hospital / Location
Brain surgery				*Year(s) of each*	
Spinal surgery				*Year(s) of each*	
Eye surgery				*Year(s) of each*	
Receive dura mater allograft				*Year(s) of each*	
Receive corneal allograft				*Year(s) of each*	
Receive human derived pituitary growth hormone				*Year(s) of each*	
DONATE blood				*Date(s) (mm/dd/yyyy)*	
DONATE cells/tissues/organs				*Date(s) (mm/dd/yyyy)*	
Other (specify)					

First three letters of patient's last name: | | | |

EXPOSURES / RISK FACTORS (continued)

DID THE PATIENT HAVE ANY OF THE FOLLOWING EXPOSURES?

Exposure	Yes	No	Unk	If Yes, Specify as Noted	
RECEIVE a blood transfusion				*Date(s) (mm/dd/yyyy)*	*Location*
HUNT deer or elk				*Area(s) hunted*	*Year(s)*
Knowingly EAT deer or elk meat				*From where was meat obtained?*	*Year(s)*
History of definite or probable case of prion disease in a blood relative				*Relationship to patient*	*Name of disease*
Other (specify)					

TRAVEL HISTORY

Did patient live or travel outside of the U.S. (including military service) between 1980 - 1996? ☐Yes ☐No ☐Unk	*If Yes, specify all locations and dates below.*

TRAVEL HISTORY - DETAILS

Location (city, county, state, country)	Date Travel Started *(mm/dd/yyyy)*	Date Travel Ended *(mm/dd/yyyy)*

NOTES / REMARKS / OTHER SIGNIFICANT ILLNESSES:

REPORTING AGENCY

Investigator Name	*Local Health Jurisdiction*	*Telephone Number*	*Date (mm/dd/yyyy)*

First Reported By
☐Clinician ☐Laboratory ☐Other (specify):_____

EPIDEMIOLOGICAL LINKAGE

Epi-linked to known case? ☐Yes ☐No ☐Unk	*Contact Name / Case Number*

First three letters of patient's last name: | | | |

DISEASE CASE CLASSIFICATION

Disease Type

☐Sporadic CJD ☐Variant CJD ☐Other Prion Disease (specify):_____
☐Iatrogenic CJD ☐Familial Prion Disease (specify):_____

SUPPORTING DOCUMENTATION

Documentation Attached

☐Hospital discharge summary ☐MRI report ☐CSF test results ☐Brain biopsy report
☐Autopsy report ☐Neurologist report / notes ☐EEG report ☐Death certificate

STATE USE ONLY

State Case Classification

☐Definite ☐Neurologist diagnosed ☐Probable ☐Possible ☐Not a case ☐Need additional information

CASE DEFINITION

CREUTZFELDT-JAKOB DISEASE (CDPH, working definition 2012)

CLINICAL DESCRIPTION

Creutzfeldt-Jakob disease is a rapidly progressive dementia diagnosed by a neurologist as CJD or Transmissible Spongiform Encephalopathy (TSE) or a prion disease confirmed by autopsy or biopsy.

CASE CLASSIFICATION

1. Sporadic CJD

Definite:
Diagnosed by standard neuropathological techniques; and/or immunocytochemically; and/or Western blot confirmed protease-resistant PrP; and /or presence of scrapie-associated fibrils.

Neurologist diagnosed:
A neurologist's assessment that a case is a probable CJD (requires that a neurologist evaluate the clinical symptoms and the EEG/MRI/CSF results, concurs with the diagnosis of CJD AND considers that no other diagnosis is more likely)

Probable:
Rapidly progressive dementia; and at least two out of the following four clinical features:
- Myoclonus
- Visual or cerebellar signs
- Pyramidal/extrapyramidal signs
- Akinetic mutism

AND a positive result on at least one of the following laboratory tests:
- A typical EEG (periodic sharp wave complexes) during an illness of any duration; and/or
- A positive 14-3-3 cerebrospinal fluid (CSF) assay in patients with a disease duration of less than 2 years
- Magnetic resonance imaging (MRI) high signal abnormalities in caudate nucleus and/or putamen on diffusion-weighted imaging (DWI) or fluid attenuated inversion recovery (FLAIR)

AND without routine investigations indicating an alternative diagnosis.

Possible:
Progressive dementia; and at least two out of the following four clinical features:
- Myoclonus
- Visual or cerebellar signs
- Pyramidal/extrapyramidal signs
- Akinetic mutism

AND the absence of a positive result for any of the three laboratory tests that would classify a case as "probable"
AND duration of illness less than two years
AND without routine investigations indicating an alternative diagnosis.

2. Iatrogenic CJD

Progressive cerebellar syndrome in a recipient of human cadaveric-derived pituitary hormone; or sporadic CJD with a recognized exposure risk, e.g., antecedent neurosurgery with dura mater implantation.

3. Familial CJD

Definite or probable CJD plus definite or probable CJD in a first degree relative; and/or Neuropsychiatric disorder plus disease-specific PrP gene mutation.

(continued on page 6)

First three letters of patient's last name: | | | |

CASE DEFINITION (continued)

4. Variant CJD (vCJD)

Definite vCJD:
Confirmation by brain biopsy or autopsy

Suspected vCJD:

a. Age < 55 years at presentation/death
b. Psychiatric symptoms at onset and/or persistent painful sensory symptoms
c. Dementia, and development ≥ 4 months after illness onset of at least two of the following five neurologic signs: poor coordination, myoclonus, chorea, hyperreflexia, or visual signs (If persistent painful sensory symptoms exist, ≥ 4 months delay in the development of the neurologic signs is not required)
d. A normal or an abnormal EEG, but not characteristic of sporadic CJD
e. Duration of illness > 6 months
f. Routine investigations of the patient do not suggest an alternative, non-CJD diagnosis
g. No history of receipt of cadaveric human pituitary growth hormone or a dura mater graft
h. No history of CJD in a first degree relative or prion protein gene mutation in the patient
i. Bilateral pulvinar sign on MRI in the presence of above criteria
j. History of residence or travel to a BSE-affected country after 1980 increases the index of suspicion

COMMENT

Questions about reporting a case can be directed to the California Emerging Infections Program - CJD Surveillance Project at (510) 350-3399 or http://www.ceip.us/cjd.htm.

RACE DESCRIPTIONS

Race	Description
American Indian or Alaska Native	Patient has origins in **any** of the original peoples of North and South America (including Central America).
Asian	Patient has origins in **any** of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent (e.g., including Bangladesh, Cambodia, China, India, Indonesia, Japan, Korea, Malaysia, Nepal, Pakistan, the Philippine Islands, Thailand, and Vietnam).
Black or African American	Patient has origins in **any** of the black racial groups of Africa.
Native Hawaiian or Other Pacific Islander	Patient has origins in **any** of the original peoples of Hawaii, Guam, American Samoa, or other Pacific Islands.
White	Patient has origins in **any** of the original peoples of Europe, the Middle East, or North Africa.

OCCUPATION SETTING

- Childcare/Preschool
- Correctional Facility
- Drug Treatment Center
- Food Service
- Health Care - Acute Care Facility
- Health Care - Long Term Care Facility
- Health Care - Other
- Homeless Shelter
- Laboratory
- Military Facility
- Other Residential Facility
- Place of Worship
- School
- Other

OCCUPATION

- Adult film actor/actress
- Agriculture - farmworker or laborer (crop, nursery, or greenhouse)
- Agriculture - field worker
- Agriculture - migratory/seasonal worker
- Agriculture - other/unknown
- Animal - animal control worker
- Animal - farm worker or laborer (farm or ranch animals)
- Animal - veterinarian or other animal health practitioner
- Animal - other/unknown
- Clerical, office, or sales worker
- Correctional facility - employee
- Correctional facility - inmate
- Craftsman, foreman, or operative
- Daycare or child care attendee
- Daycare or child care worker
- Dentist or other dental health worker
- Drug dealer
- Fire fighting or prevention worker
- Flight attendant
- Food service - cook or food preparation worker
- Food service - host or hostess
- Food service - server
- Food service - other/unknown
- Homemaker
- Laboratory technologist or technician
- Laborer - private household or unskilled worker
- Manager, official, or proprietor
- Manicurist or pedicurist
- Medical - emergency medical technician or paramedic
- Medical - health care worker
- Medical - medical assistant
- Medical - pharmacist
- Medical - physician assistant or nurse practitioner
- Medical - physician or surgeon
- Medical - nurse
- Medical - other/unknown
- Military
- Police officer
- Professional, technical, or related profession
- Retired
- Sex worker
- Stay at home parent/guardian
- Student - preschool or kindergarten
- Student - elementary or middle school
- Student - high school
- Student - college or university
- Student - other/unknown
- Teacher/employee - preschool or kindergarten
- Teacher/employee - elementary or middle school
- Teacher/employee - high school
- Teacher/instructor/employee - college or university
- Teacher/instructor/employee - other/unknown
- Unemployed - seeking employment
- Unemployed - not seeking employment
- Unemployed - other/unknown
- Volunteer
- Other
- Refused
- Unknown