

CREUTZFELDT-JAKOB DISEASE (CJD) AND TRANSMISSIBLE SPONGIFORM ENCEPHALOPATHY (TSE) CASE REPORT

CASE DEFINITION AND SUPPORTING DOCUMENTATION										
<i>Case Definition: A rapidly progressive dementia diagnosed by a neurologist as Creutzfeldt-Jakob disease or TSE</i>										
Documentation (attach to case report form and check all that apply) <input type="checkbox"/> Hospital Discharge Summary <input type="checkbox"/> MRI Report <input type="checkbox"/> 14-3-3 Test Results <input type="checkbox"/> Brain Biopsy Report <input type="checkbox"/> Autopsy Report <input type="checkbox"/> Neurologist Report / Notes <input type="checkbox"/> EEG Report <input type="checkbox"/> Death Certificate										
DEMOGRAPHIC INFORMATION										
Patient Name - Last			First Name		Middle Initial	Date of Birth ____/____/____		Age <input type="checkbox"/> Days <input type="checkbox"/> Months <input type="checkbox"/> Years		Gender <input type="checkbox"/> Male <input type="checkbox"/> Female
Address (number, street)				Apt./Unit No.		County			Telephone Numbers work () home() cell ()	
City			State		ZIP Code					
Race (check all that apply) <input type="checkbox"/> African-American/Black <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Other (specify): _____ <input type="checkbox"/> Unknown							Ethnicity (check one) <input type="checkbox"/> Non-Hispanic/Non-Latino <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Unk			
If Asian, check all that apply <input type="checkbox"/> Asian Indian <input type="checkbox"/> Cambodian <input type="checkbox"/> Chinese <input type="checkbox"/> Filipino <input type="checkbox"/> Hmong <input type="checkbox"/> Japanese <input type="checkbox"/> Korean <input type="checkbox"/> Laotian <input type="checkbox"/> Thai <input type="checkbox"/> Vietnamese <input type="checkbox"/> Other (specify): _____										
If Pacific Islander, check all that apply <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Guamanian <input type="checkbox"/> Samoan <input type="checkbox"/> Other (specify): _____										
Country of Birth					If not U.S.-born, Date of Arrival in U.S. ____/____/____					
Occupation										
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.)						Location as of ____/____/____				
CLINICAL INFORMATION										
Physician Name - Last Name					First Name			Telephone Number ()		
Onset Date ____/____/____		Date of CJD Diagnosis ____/____/____			Name and Location of Hospital where CJD Diagnosis was made:					
Hospitalized? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk	If yes, Hospital Name		City	State	Zip Code	Medical Record #	Telephone # ()	Admit Date ____/____/____	Discharge Date ____/____/____	
Patient Transferred? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk	If yes, Hospital Name		City	State	Zip Code	Medical Record #	Telephone # ()	Admit Date ____/____/____	Discharge Date ____/____/____	
Was the patient seen by a neurologist? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk				If yes, Neurologist's Name				Neurologist's Telephone Number ()		
Diagnosis of CJD made by a neurologist? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk				If no, Diagnosing Physician Name and Specialty				Physician's Telephone Number ()		
Other Significant Illnesses:										
Outcome <input type="checkbox"/> Survived (as of ____/____/____) <input type="checkbox"/> Died (date ____/____/____) <input type="checkbox"/> Unk State in which death occurred:_____										
Is CJD listed as a cause of death on the death certificate? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk If no, what was the primary cause of death on certificate?_____										

LABORATORY INFORMATION (attach copies of lab tests performed)

Procedure / Test	Yes	No	Unk	If yes, specify as noted
EEG performed?				Results:
MRI performed?				Results:
CSF tested for 14-3-3 protein?				Lab report #1: Date ___/___/___ Was blood found in the sample? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Results: <input type="checkbox"/> Elevated <input type="checkbox"/> Not elevated <input type="checkbox"/> Ambiguous <input type="checkbox"/> Unknown Lab report #2: Date ___/___/___ Was blood found in the sample? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Results: <input type="checkbox"/> Elevated <input type="checkbox"/> Not elevated <input type="checkbox"/> Ambiguous <input type="checkbox"/> Unknown CSF specimens sent to the National Prion Disease Pathology Surveillance Center? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk If no, which laboratory? _____
Brain biopsy performed?				Date of biopsy: ___/___/___ Sent to NPDPS? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Results: Western Blot: <input type="checkbox"/> Abnormal Prion Protein present <input type="checkbox"/> Abnormal Prion Protein NOT present Immunohistochemistry: <input type="checkbox"/> Positive <input type="checkbox"/> Negative Diagnosis: <input type="checkbox"/> CJD <input type="checkbox"/> Sporadic CJD <input type="checkbox"/> Variant CJD <input type="checkbox"/> Familial CJD <input type="checkbox"/> Other: _____
Autopsy performed?				Date of autopsy: ___/___/___ Hospital where autopsy performed: _____ Autopsy Physician name: _____ Specimens sent to NPDPS? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Results: Western Blot: <input type="checkbox"/> Abnormal Prion Protein present <input type="checkbox"/> Abnormal Prion Protein NOT present Immunohistochemistry: <input type="checkbox"/> Positive <input type="checkbox"/> Negative Diagnosis: <input type="checkbox"/> CJD <input type="checkbox"/> Sporadic CJD <input type="checkbox"/> Variant CJD <input type="checkbox"/>

Other (specify): e.g., CSF results, HIV results, PCR results, etc.

EPIDEMIOLOGIC INFORMATION

Exposures / Risk Factors

Did the patient undergo any of the surgical procedures listed before onset of the current illness?

Procedure	Yes	No	Unk	If yes, specify year(s) of each
Brain Surgery				
Spinal Surgery				
Eye Surgery				
Receive dura mater allograft				
Receive corneal allograft				
Receive human derived pituitary growth hormone				

Other (specify):

Did the patient have the following exposures?

Activity	Yes	No	Unk	If yes, specify as noted
RECEIVE a blood transfusion				Date(s): _____ Location(s): _____
DONATE blood				Date(s): _____ Location(s): _____
HUNT deer or elk				Area(s) hunted and year(s): _____
Knowingly EAT deer or elk meat				Year(s) and source location(s) of meat origin: _____
History of definite or probable case of prion disease in a blood relative				Relationship to patient: _____ Name of disease: _____
Epi-Linked to known case				Specify link type: <input type="checkbox"/> Family <input type="checkbox"/> Surgery <input type="checkbox"/> Other: _____

Other (specify):

