Arizona Department of Health Services

Send or Fax to:
ADHS Infectious Disease Epidemiology
150 North 18th Ave, Suite 140
Phoenix, Arizona 85007-3237
(602) 364-3199 Fax

Outbreak Name: _____

Part of National Outbreak? ☐Yes

Epi-linked to confirmed case? ☐ Yes MEDSISID_____

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

PATIENT INFORMATION

MEDSIS Case No: _____

County: _____

☐ Confirmed ☐ Probable

☐ Suspect ☐ Ruled Out

☐ Lost to follow up

CJD Classification
☐ Iatrogenic CJD
☐ Familial prion disease;
specify _____
☐ Sporadic CJD (indicate whether the diagnosis is one of the following)

Name (last, first) _____

Street address _____

City _____ State _____ Zip _____

Mailing address _____

Phone _____ Alt. Phone _____

Occupation:_____

Place of Birth:

State _____ County _____
Country _____

Birthdate ____ / ____ / ____ or age _____ Sex: ☐ Male ☐ Female ☐ Unknown/Other

Ethnicity: ☐ Hispanic ☐ Non-Hispanic ☐ Unknown
Race: ☐ White ☐ African American ☐ Native Hawaiian/Pac Islander
☐ Asian ☐ Amer Indian / AK Native ☐ Other _____

REPORT SOURCE

Initial report date: _____

Reporter: _____

Reporter org.: _____

Reporter phone: _____

Provider name _____

Provider org.: _____

Provider phone: _____

Family Contact:

Name of family contact _____ Phone _____

Has the family been contacted? ☐ Yes ☐ No

Has the family indicated that the health department may contact them again?
☐ Yes, may contact ☐ No, may not contact ☐ No indication has been made by family
☐ Unknown ☐ Other (specify) _____

CLINICAL INFORMATION

Date of Onset of symptoms : ___ / ___ / ____ ☐ Unknown

Date of CJD diagnosis: ___ / ___ / ____ ☐ Unknown

Was patient seen by a neurologist? ☐ Y ☐ N ☐ UK

If yes, Neurologist's Name _____
Phone Number _____

Diagnosis of CJD made by a neurologist? ☐ Y ☐ N ☐ UK

If no, Diagnosing Physician Name _____
Phone Number _____

Hospital Name where diagnosis was made _____

Was patient hospitalized? ☐ Y ☐ N ☐ UK

If yes, Hospital Name _____ Street address _____ City _____ State _____ Zip _____

Medical Record # _____ Admit Date ___/___/___ Discharge Date ___/ ___/___

Outcome ☐ Survived (as of ___ / ___ / ____) ☐ Died (as of ___ / ___ / ____) ☐ Unknown

Is CJD listed as a cause of death on the death certificate? ☐ Y ☐ N ☐ UK

Primary cause of death on death certificate _____

Y=Yes **N=No/Negative** **UK=Unknown** **NA=Not Applicable**

CJD AND TSE

Name (Last, First) _____

CLINICAL INFORMATION (continued)

Signs and Symptoms: Did the patient have any of the following?

Y	N	UK		Y	N	UK	
☐	☐	☐	Progressive dementia	☐	☐	☐	Cerebellar signs (e.g. poor coordination/ ataxia)
☐	☐	☐	Myoclonus	☐	☐	☐	Akinetic mutism
☐	☐	☐	Visual deficits	☐	☐	☐	Pyramidal/extrapyramidal signs

LABORATORY TESTING (attach copies of lab tests performed)

Procedure/ Test	Y	N	UK	*If yes, specify as noted*
EEG performed ?				Results: Date ___/___/___
MRI performed ?				Results: Date ___/___/___
CSF tested for 14-3-3 protein ?				Lab report # 1: Date ___/___/___ Was blood found in the sample? ☐ Y ☐ N ☐ UK Results: ☐ Elevated ☐ Not elevated ☐ Ambiguous ☐ Unknown Lab report # 2: Date ___/___/___ Was blood found in the sample? ☐ Y ☐ N ☐ UK Results: ☐ Elevated ☐ Not elevated ☐ Ambiguous ☐ Unknown CSF specimens sent to National Prion Disease Pathology Surveillance center? ☐ Y ☐ N ☐ UK
Brain biopsy performed ?				Date of biopsy: ___/___/___ Sent to NPDPSC? ☐ Y ☐ N ☐ UK Results: Western Blot: ☐ Abnormal Prion Protein present ☐ Abnormal Prion Protein NOT present Immunohistochemistry : ☐ Positive ☐ Negative
Autopsy performed ?				Date of autopsy: ___/___/___ Hospital where autopsy performed: _____ Sent to NPDPSC? ☐ Y ☐ N ☐ UK Results: Western Blot: ☐ Abnormal Prion Protein present ☐ Abnormal Prion Protein NOT present Immunohistochemistry : ☐ Positive ☐ Negative
Genetic testing?				Was blood/tissue sent to NPDPSC for genetic testing? ☐ Y ☐ N ☐ UK If yes, Date of lab report: ___/___/___ Results: PRNP mutation present? ☐ Y ☐ N ☐ UK Codon 129? ☐ Methionine/Methionine ☐ Methionine/Valine ☐ Valine/Valine ☐ Unknown
Were other types of testing performed?				If yes, what kind of test was performed and what were the results? _____ _____

Y=Yes **N=No/Negative** **UK=Unknown** **NA=Not Applicable**

CJD AND TSE

Name (Last, First) _____

EPIDEMIOLOGICAL INFORMATION

Exposures/ Risk Factors

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

Procedure	Y	N	UK	*If yes, specify year(s) of each*
Brain Surgery				
Spinal Surgery				
Eye Surgery				
Sinus Surgery				

Did the patient ever receive:

A dura matter allograft?				
A corneal allograft?				
Human derived pituitary growth hormone?				First year of receipt _____ Last year of receipt _____

Did the patient have the following exposures?

Activity	Y	N	UK	*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):
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: ☐ Family ☐ Surgery ☐ Other:

Other (specify):

Travel History

Did the patient live or travel outside the US (including military service) between 1980-1996? ☐ Y ☐ N ☐ UK

If yes, specify all locations and dates below.

Location (city, country)	*Dates of Residence/ Travel*
	___/___/___ **to** ___/___/___
	___/___/___ **to** ___/___/___
	___/___/___ **to** ___/___/___

ADDITIONAL NOTES and INFORMATION

Y=Yes **N=No/Negative** **UK=Unknown** **NA=Not Applicable**

CJD AND TSE

Name (Last, First) _____

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DIAGNOSTIC CRITERIA

Creutzfeldt-Jakob Disease (CJD) is a fatal disease characterized by progressive dementia and the following neurological symptoms:

- Myoclonus
- Visualor cerebellar signs
- Pyramidal/extrapyramidal signs
- Akinetic mutism

Laboratory Criteria for Diagnosis

Confirmed:

- Detection of characteristic lesions by examination of frozen brain tissue. This diagnosis can be made in the US only by the National Prion Disease Pathology Surveillance Center
- Detection of abnormal prion protein by Western blot testing performed on frozen brain tissue, or by immunohistochemistry /histology performed on fixed tissue

Confirmed:

- Detection of 14-3-3 protein in CSF
- Genetic analysis suggestive of mutation associated with CJD
- Detection of characteristic patterns by EEG or MRI

Case Classification

CONFIRMED: A case that meets at least one of the confirmatory laboratory criteria and only when performed by the NPDPSC

PROBABLE: A case that meets one of the probable laboratory criteria and in which three of the five clinical findings above are present. Findings should include progressive dementia with clinical duration lasting < 2 years.

SUSPECT: A case that meets one of the probable laboratory criteria and in which no clinical information is known.

CJD Cassifications

Iatrogenic CJD

- Progressive cerebellar syndrome in a recipient of human cadaveric-dervieved hormone
- A CJD recognized exposure risk (i.e. antecedent neurosurgery with dura matter implantation, corneal transplants, brain surgery)

Familial CJD

- Confirmed or Probable CJD in a first degree relative

Familial CJD

- No evidence of iatrogenic and familial CJD

ACTIONS TAKEN

☐ No risk factors/exposures could be identified

☐ Patient could not be interviewed/LTF

☐ Case is part of known outbreak

Outbreak Name: _____

☐ Epi-linked to confirmed case?

MEDISIS ID of confirmed case: _____

☐ Education provided to case/contacts/facilities (Medication)

☐ Follow-up to ensure compliance with treatments

☐ Follow-up on contacts who may have been exposed

☐ Other: _____

INVESTIGATOR(S): _____ **DATE:** ___/___/___ **DATE CLOSED:** ___/___/___

Y=Yes **N=No/Negative** **UK=Unknown** **NA=Not Applicable**