



Human Prion Disease

(Rare Disease of Public Health Significance)

LHJ Use ID _____

Please enter the case in PHIMS as a Rare Disease of Public Health Significance and send/fax this form to DOH Communicable Disease Epidemiology.

Investigator _____

Phone/email _____

Investigation complete date

____/____/____

Disease:

County

REPORT SOURCE

Initial report date ____/____/____

Reporter (check all that apply)

NPDPS lab Hospital

Public health agency Health Care Provider

Other _____

OK to talk to surviving relative? Yes No DK

Date of interview ____/____/____

Investigation start date
____/____/____

Reporter name _____ Reporter phone _____

HCP1 name _____ HCP1 phone _____

HCP2 name _____ HCP2 phone _____

Notes: _____

PATIENT INFORMATION

Name (last, first) _____

Address _____ Homeless

City/State/Zip _____

Next of kin: Name _____

Next of kin: Phone _____

Spouse Parent Child Sibling Legal guardian

Other relative _____ Other _____

Primary occupation _____ Employer/worksite _____

Birth date ____/____/____ Age _____

Gender F M Other Unk

Ethnicity Hispanic or Latino

Not Hispanic or Latino Unk

Race (check all that apply)

Amer Ind/AK Native Asian

Native HI/other PI Black/Afr Amer

White Other Unk

CLINICAL INFORMATION

Onset date (mm/yy) ____/____ Derived

Diagnosis date ____/____/____

Illness duration _____ days/months/years

Clinical Findings

First symptom(s) _____

Y N DK NA

Neurodegenerative disease

Progressive dementia

Cerebellar signs (e.g., poor coordination/ataxia)

Visual abnormality

Myoclonus

Pyramidal signs (e.g., hyperreflexia, spasticity)

Chorea

Dystonia

Other extrapyramidal signs (e.g., rigidity, tremor, shuffling gait)

Akinetic mutism

Progressive neuropsychiatric disorder

Early psychiatric symptom(s) (anxiety, apathy, delusions, depression, and/or withdrawal)

Persistent painful sensory symptom(s) (frank pain and/or dysesthesia)

Notes on clinical symptoms _____

Clinical Findings

Y N DK NA

EEG performed Date ____/____/____

EEG with periodic sharp wave complexes

EEG result _____

MRI performed Date ____/____/____

Diffusion weighted MRI

MRI result _____

Indication of an alternative, non-prion disease diagnosis (i.e., subarachnoid hemorrhage, encephalitis, stroke with acute infarction, multi-infarct dementia with acute infarction, brain neoplasm, paraneoplastic neurological disorder)

Hospitalization

Y N DK NA

Hospitalized at least overnight for this illness

Hospital name/City _____

Admit date ____/____/____ Discharge date ____/____/____

Y N DK

Died from illness Date of death ____/____/____

Autopsy Age at death _____

County of death _____

Laboratory

Y N DK NA

- 14-3-3 protein test performed on CSF
 Test date ___/___/___
 Elevated Ambiguous Not elevated
- Brain biopsy performed
 Date of procedure ___/___/___
 Laboratory where tissue sent:
 Nat Prion Disease Path Surv Center (NPDPSC)
 Other laboratory: _____

Laboratory

Y N DK NA

- Brain autopsy performed
 Date of autopsy ___/___/___
 Laboratory where tissue sent:
 Nat Prion Disease Path Surv Center (NPDPSC)
 Other laboratory: _____
- Neuropathologic confirmation
- Confirmation of protease-resistant prion protein by immunohistochemistry or Western blot
- Presence of scrapie-associated fibrils

POSSIBLE SOURCES

Predisposing Factors

Y N DK NA

- Family history of prion disease in a 1^o relative
- Prion gene mutation

Exposures

Y N DK NA Has the patient ever...

- Spent 3 months or more in the U.K. since 1980?
- Lived outside the United States
 Country _____ Specific Months/Year _____
 Country _____ Specific Months/Year _____
 Country _____ Specific Months/Year _____

Y N DK NA Has the patient ever...

- Received human-derived pituitary hormones (e.g., growth hormone)
 Dates ___/___/___ to ___/___/___
- Received a dura mater or corneal allograft
 Date ___/___/___
- Had neurosurgery (on brain, spinal cord or eyes)
 Date ___/___/___
 Anatomic Site _____
 Hospital name/city _____

CASE CLASSIFICATION

- Sporadic CJD: Definite Probable Possible
- Iatrogenic CJD: Definite Probable
- Familial CJD: Definite Probable
- Variant CJD: Definite Probable Possible

- Other prion disease _____
- Prion disease unlikely
- Cannot be determined/provider report only

Source(s) of Patient History

- Chart review Provider interview Patient interview
- Relative/friend interview Name _____ Relationship _____

NOTES

PUBLIC HEALTH ISSUES

Y N DK NA

- Case donated organs or tissues
 Date ___/___/___
 Facility _____
 Organs/tissues donated _____
- Case underwent neurosurgery or eye surgery
 Date ___/___/___
 Facility _____
 Procedure _____

PUBLIC HEALTH ACTIONS

Y N DK NA

- Blood/tissue/organ program notified
 Date ___/___/___
- Surgical facility notified
 Date ___/___/___
- Report sent to CDC
 Date ___/___/___