



Human Prion Disease

County _____

Case name (last, first) _____
 Birth date ___/___/___ Sex at birth F M Other Alternate name _____
 Phone _____ Email _____
 Address type Home Mailing Other Temporary Work
 Street address _____
 City/State/Zip/County _____
 Residence type (incl. Homeless) _____ WA resident Yes No

ADMINISTRATIVE

Investigator _____
 LHJ Case ID (optional) _____
 LHJ notification date ___/___/___
Classification Classification pending Confirmed
 Not reportable Probable Ruled out Suspect
 Investigation status
 In progress
 Complete
 Complete – not reportable to DOH
 Unable to complete Reason _____
 Investigation start date ___/___/___
 Investigation complete date ___/___/___
 Case complete date ___/___/___
 Outbreak related Yes No
 LHJ Cluster ID _____ Cluster Name _____

DEMOGRAPHICS

Age at symptom onset _____ Years Months
Ethnicity Hispanic or Latino Not Hispanic or Latino Unk
Race (check all that apply) Unk Amer Ind/AK Native
 Asian Black/African Amer Native HI/other PI
 White Other _____
 Primary language _____
 Interpreter needed Yes No Unk
 Employed Yes No Unk Occupation _____
 Industry _____ Employer _____
 Work site _____ City _____
 Student/Day care Yes No Unk
 Type of school Preschool/day care K-12 College
 Graduate School Vocational Online Other
 School name _____
 School address _____
 City/State/County _____ Zip _____
 Phone number _____ Teacher's name _____

REPORT SOURCE

Initial report source _____
 LHJ _____
 Reporter organization _____
 Reporter name _____
 Reporter phone _____
 All reporting sources (list all that apply)

COMMUNICATIONS

Primary HCP name _____
 Phone _____
 OK to talk to patient (If Later, provide date)
 Yes Later ___/___/___ Never
 Date of interview attempt ___/___/___
 Complete Partial Unable to reach
 Patient could not be interviewed
 Alternate contact Parent/Guardian Spouse/Partner
 Friend Other _____
 Contact name _____
 Contact phone _____

CLINICAL INFORMATION

Complainant ill Yes No Unk Symptom Onset ___/___/___ Derived Diagnosis date ___/___/___
 Illness duration _____ Days Weeks Months Years Illness is still ongoing Yes No Unk
Classification Sporadic Type Definite Probable Possible
 Iatrogenic Type Definite Probable
 Familial Type Definite Probable
 Variant Type Definite Probable Possible
Y N Unk
 Prion disease unlikely
 Indication of an alternative, non-prion disease diagnosis (e.g., subarachnoid hemorrhage, encephalitis, stroke with acute infarction, multi-infarct dementia with acute infarction, brain neoplasm, paraneoplastic neurological disorder)
 Specify _____

Clinical Features

Y N Unk
 Patient seen by a neurologist

Source of patient history Chart review Patient interview Provider interview Unk Other _____ Relative/friend interview

Name of interviewee _____

Relationship to patient _____

First symptom(s) _____

Y N Unk Neurodegenerative disease **Rapidly progressive dementia** **Myoclonus** **Visual abnormality** Hallucinations Hemianopsia Opsoclonus Blindness Visual field cut/deficit Diplopia **Cerebellar signs** Ataxia Movement tremor Nystagmus **Pyramidal signs** Spasticity Hyperreflexia Clonus Spastic paralysis Babinski's sign Upper motor neuron weakness Hemiplegia **Akinetic mutism** **Extrapyramidal signs** Chorea Dystonia Bradykinesia/hypokinesia Tremor Hypomimia Shuffling gait Rigidity Ballismus/hemiballismus Choreoathetosis Postural instability Progressive neuropsychiatric disorder Psychiatric symptoms at illness onset Delusions Apathy Anxiety Depression Withdrawal Persistent painful sensory symptoms Frank pain Dysesthesia**Predisposing Conditions****Y N Unk** **Family history of confirmed or probable prion disease in a first degree relative** Prion protein (PrP) gene mutation known Specify _____**Clinical Testing****Y N Unk** MRI performed Date ___/___/___ Result _____ High signal in caudate/putamen on magnetic resonance imaging (MRI) brain scan or at least two cortical regions (temporal, parietal, occipital) either on DWI or FLAIR* Bilateral FLAIR hyperintensities involving the pulvinar thalamic nuclei (hockey stick sign) EEG performed Date ___/___/___ Result _____ **EEG with periodic sharp wave complexes**

* FLAIR: Fluid attenuated inversion recovery; DWI: Diffusion-weighted imaging

Hospitalization**Y N Unk** Hospitalized at least overnight for this illness Facility name _____

Hospital admission date ___/___/___ Discharge ___/___/___ HRN _____

Disposition Another acute care hospital Facility name _____ Died in hospital Long term acute care facility Facility name _____ Long term care facility Facility name _____ Non-healthcare (home) Unk Other _____ Still hospitalized As of ___/___/___**Y N Unk** Died of this illness Death date ___/___/___ Please fill in the death date information on the Person Screen Autopsy performed Date of autopsy ___/___/___ Specimens sent to NPDPS Death certificate lists disease as a cause of death or a significant contributing conditionLocation of death Outside of hospital (e.g., home or in transit to the hospital) Emergency department (ED) Inpatient ward ICU Other _____**RISK AND RESPONSE (ask about lifetime exposures unless otherwise specified)****Travel****Y N Unk** Spent 3 months or more in the U.K. since 1980 Ever lived outside the United States Country _____ Month/year _____

Risk and Exposure Information

Y N Unk

- Received human-derived pituitary hormones (e.g., growth hormone) Start date ___/___/___ End date ___/___/___
- Recognized exposure risk (e.g., antecedent neurosurgery with dura matter implantation) Date ___/___/___
Anatomic site _____ Hospital name/city _____
- Received a dura matter or corneal allograft Date ___/___/___
- Dressed hunted deer/elk Year(s) of exposure _____
Area(s) where hunting occurred _____
- Consumed venison from deer/elk Year(s) of consumption _____
Where did meat originate _____
- Blood/tissue/organ product implicated Specify _____

Exposure and Transmission Summary

Likely geographic region of exposure In Washington – county _____ Other state _____
 Not in US - country _____ Unk

International travel related During entire exposure period During part of exposure period No international travel

Suspected exposure type Foodborne Animal related Blood products Health care associated Unk
 Other _____

Describe _____

Exposure summary _____

Public Health Issues

Y N Unk

- Case has history of neurosurgery or eye surgery Date ___/___/___
Anatomic site _____
Facility name _____
Procedure _____
- Case donated organs or tissues Date ___/___/___
Organs/tissues donated _____
Facility name _____

Public Health Interventions/Actions

Y N Unk

- Autopsy/biopsy discussed with medical provider (if notification occurred before patient's death)
- Infection control measures discussed with facilities ICP (to be done in all cases)
- Blood/tissue/organ program notified Date ___/___/___
- Surgical facility notified Date ___/___/___

NOTES

LAB RESULTS

Lab report information

Lab report reviewed – LHJ

WDRS user-entered lab report note _____

Submitter _____

Performing lab for entire report _____

Referring lab _____

Specimen

Specimen identifier/accession number _____

Specimen collection date ___/___/___ **Specimen received date** ___/___/___

WDRS specimen type _____

WDRS specimen source site _____

WDRS specimen reject reason _____

Test performed and result

WDRS test performed _____

WDRS test result, coded _____

WDRS test result, comparator _____

WDRS result, numeric only (enter only if given, including as necessary **Comparator** and **Unit of measure**) _____

WDRS unit of measure _____

Test method _____

WDRS interpretation code _____

Test result – Other, specify _____

WDRS result summary Positive Negative Indeterminate Equivocal Test not performed Pending

Test result status Final results; Can only be changed with a corrected result

Preliminary results

Record coming over is a correction and thus replaces a final result

Results cannot be obtained for this observation

Specimen in lab; results pending

Result date ___/___/___

Upload document

Ordering Provider

WDRS ordering provider _____

Ordering facility

WDRS ordering facility name _____