



# Human Prion Disease

County \_\_\_\_\_

Case name (last, first) \_\_\_\_\_  
 Birth date \_\_\_/\_\_\_/\_\_\_ Age at symptom onset \_\_\_\_\_  Years  Months  
 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 \_\_\_\_\_ LHM Case ID (optional) \_\_\_\_\_

LHM notification date \_\_\_/\_\_\_/\_\_\_

### Classification

Classification pending  Confirmed  Investigation in progress  Not reportable  Probable  Ruled out  Suspect

### Investigation status

Complete  Complete – not reportable to DOH  Unable to complete Reason \_\_\_\_\_  In progress

**Dates:** Investigation start \_\_\_/\_\_\_/\_\_\_ Investigation complete \_\_\_/\_\_\_/\_\_\_ Record complete \_\_\_/\_\_\_/\_\_\_ **Case complete** \_\_\_/\_\_\_/\_\_\_

## REPORT SOURCE

Initial report source \_\_\_\_\_ LHM \_\_\_\_\_

Reporter organization \_\_\_\_\_

Reporter name \_\_\_\_\_ Reporter phone \_\_\_\_\_

All reporting sources (list all that apply) \_\_\_\_\_

## DEMOGRAPHICS

Sex at birth:  Female  Male  Other  Unknown

Do you consider yourself (your child) Hispanic, Latino/a, or Latinx?

**Ethnicity**  Hispanic, Latino/a, Latinx  Non-Hispanic, Latino/a, Latinx  Patient declined to respond  Unknown

What race or races do you consider yourself (your child)? You can be as broad or specific as you'd like (check all responses):

**Race**  Amer Ind/AK Native (*specify:*  Amer Ind **and/or**  AK Native)  Asian  Black or African American  
 Native HI/Pacific Islander (*specify:*  Native HI **and/or**  Pacific Islander)  White  Patient declined to respond  Unk

Additional race information:

Afghan  Afro-Caribbean  Arab  Asian Indian  Bamar/Burman/Burmese  Bangladeshi  Bhutanese  
 Central American  Cham  Chicano/a or Chicanx  Chinese  Congolese  Cuban  Dominican  Egyptian  
 Eritrean  Ethiopian  Fijian  Filipino  First Nations  Guamanian or Chamorro  Hmong/Mong  
 Indigenous-Latino/a or Indigenous-Latinx  Indonesian  Iranian  Iraqi  Japanese  Jordanian  Karen  
 Kenyan  Khmer/Cambodian  Korean  Kuwaiti  Lao  Lebanese  Malaysian  Marshallese  Mestizo  
 Mexican/Mexican American  Middle Eastern  Mien  Moroccan  Nepalese  North African  Oromo  
 Pakistani  Puerto Rican  Romanian/Rumanian  Russian  Samoan  Saudi Arabian  Somali  
 South African  South American  Syrian  Taiwanese  Thai  Tongan  Ugandan  Ukrainian  
 Vietnamese  Yemeni  Other: \_\_\_\_\_

What is your (your child's) preferred language? Check one:

Amharic  Arabic  Balochi/Baluchi  Burmese  Cantonese  Chinese (unspecified)  Chamorro  Chuukese  
 Dari  English  Farsi/Persian  Fijian  Filipino/Pilipino  French  German  Hindi  Hmong  Japanese  
 Karen  Khmer/Cambodian  Kinyarwanda  Korean  Kosraean  Lao  Mandarin  Marshallese  Mixteco  
 Nepali  Oromo  Panjabi/Punjabi  Pashto  Portuguese  Romanian/Rumanian  Russian  Samoan  
 Sign languages  Somali  Spanish/Castilian  Swahili/Kiswahili  Tagalog  Tamil  Telugu  Thai  Tigrinya  
 Ukrainian  Urdu  Vietnamese  Other language: \_\_\_\_\_  Patient declined to respond  Unknown

Interpreter needed  Yes  No  Unk

**EMPLOYMENT AND SCHOOL**

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 \_\_\_\_\_

**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 \_\_\_\_\_  
 Name \_\_\_\_\_ Phone \_\_\_\_\_

Outbreak related  Yes  No LHJ Cluster ID \_\_\_\_\_ Cluster Name \_\_\_\_\_

**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 NPDPSC   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 \_\_\_\_\_  UnkInternational travel related  During entire exposure period  During part of exposure period  No international travelSuspected 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  PendingTest 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 \_\_\_\_\_

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