Washington State Department of Health

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 _____ LHJ Case ID (optional) _____

LHJ 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 _____ LHJ _____

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 childs) 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

Case Name _____ LHJ Case ID _____

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
☐ Iatrongenic 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

Case Name _____ LHJ Case ID _____

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 condition

Location 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 _____

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