

Prion Diseases

Information for infection preventionists

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Report all prion diseases

Confirmed and suspected cases of prion disease, also called transmissible spongiform encephalopathies (TSEs), are reportable to the patient's local health department by state statute. Cases should be reported via the Wisconsin Electronic Disease Surveillance System (WEDSS) or faxed to Wisconsin Division of Public Health (DPH) using an [Acute and Communicable Diseases case report, F-44151 \(Word\)](#). This includes all prion-related diseases, including Creutzfeldt-Jakob disease (CJD), fatal insomnia (FI), Gerstman- Straußler-Scheinker syndrome (GSS), and variably protease-sensitive prionopathy (VPSPr).



Criteria for reporting a suspect case of prion disease in Wisconsin

A prion-disease related disorder, such as CJD, should be suspected and reported to DPH in the following cases:

Any patient with dementia of early onset (less than 55 years).

Or

Rapidly progressive dementia occurring at any age with one or more of the following:

- Movement disorders (for example, myoclonus, ataxia).
- Painful sensory symptoms.
- Visual disturbances.



Information to upload to WEDSS or fax to DPH at 608-251-3035

- Basic demographic information
- Current status of the patient
- Name and contact information for the health care provider overseeing the patient's care
- Medical records including:
 - Neurologic referrals and notes
 - History and physical exam
 - Lab work
 - Electroencephalograms
 - Imaging reports
 - Any information that will help clarify the sequence of events leading to this potential diagnosis
 - Cerebrospinal fluid testing results



DPH strongly advises testing at the National Prion Disease Pathology Surveillance Center (NPDSC)

To arrange an autopsy on a suspect case of prion disease or for autopsy related questions contact NPDSC at:

Phone: 216-368-0587

Emergency (nights and weekends only): 216-647-8148

Email: cjdsurveillance@uhhospitals.org

Website: <http://case.edu/med/pathology/centers/npdpsc/protocols.html>

