



REPORT ALL PRION DISEASES



Confirmed and suspected cases of prion disease (also called transmissible spongiform encephalopathies) are legally reportable to the Wisconsin Division of Public Health (DPH). Cases should be reported via WEDSS. This includes all prion-related diseases, including Creutzfeldt-Jakob disease (CJD), fatal familial insomnia, and Gerstmann-Straüssler-Scheinker syndrome.

Criteria for Reporting a Suspect Case of Prion Disease in Wisconsin

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

Any patient with dementia of early onset (<55 years)

OR

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

- Movement disorders (e.g., myoclonus, ataxia)
- Painful sensory symptoms
- Visual disturbances

What to expect when reporting a case to DPH

The epidemiologist will request basic demographic information and current status of the patient as well as the name and contact information for the patient's next of kin, or whoever is speaking for the patient.



DPH will request that medical records be faxed to them, including neurologic referrals and notes, H&P, lab work, EEGs, imaging reports, and anything else that will help clarify the sequence of events leading to this potential diagnosis.



DPH can advise on specimen testing at the National Prion Disease Pathology Surveillance Center at Case Western University (<http://case.edu/med/pathology/centers/npdpssc/protocols.html>), and can assist in arranging autopsies.



To arrange an autopsy on a suspect case of prion disease, or talk with the

DPH Prion Program, contact:

Lorna Will, 608-267-0401, OR Rachel Klos, 608-266-2154

BUREAU OF COMMUNICABLE DISEASES

<https://www.dhs.wisconsin.gov/dph/bcd.htm> | DHSDPHBCD@dhs.wi.gov

Wisconsin Department of Health Services | Division of Public Health

