

The National Prion Disease Pathology Surveillance Center (www.cjdsurveillance.com)
Supported by the Centers for Disease Control and Prevention (CDC)

Dear Clinician:

The National Prion Disease Pathology Surveillance Center (NPDPS) monitors the occurrence of prion disease through characterization of brain tissue pathology from cases clinically suspected of Creutzfeldt-Jakob disease (CJD). As the director of the NPDPS, I want to make you aware of the following, which may be helpful in your work with current and future cases of suspected CJD:

- The 14-3-3 and Tau tests performed on cerebrospinal fluid do not definitively diagnose CJD and other prion diseases.
- Autopsy provides the only method to firmly diagnose CJD and to fully classify the etiology of CJD (sporadic, familial, or acquired by infection as in iatrogenic, or variant CJD). Autopsy also allows for the identification of atypical cases and possible novel sources of infection such as chronic wasting disease of elk and deer.
- Autopsies help to further our understanding of CJD. Tissues acquired at autopsy by the Center are made available to laboratories to do prion research.
- Ideally, autopsies should be performed within 24 hours post mortem. However, NPDPS has successfully diagnosed cases autopsied up to seven days post mortem.
- NPDPS offers a free autopsy coordination service. We make all of the arrangements, including locating the pathologist, arranging for transportation if necessary, and coordinating with the funeral home. NPDPS will cover all costs associated with the autopsy.
- Pre-arranging the autopsy with NPDPS can alleviate some of the stress on the family and can result in a more rapid and efficient autopsy process. NPDPS staff are available to make autopsy arrangements at any time after the diagnosis of suspected CJD has been made.
- Our autopsy network includes major health centers throughout the United States. In most cases, an autopsy can be arranged and completed within 24 hours, including any necessary transportation. In the event of any delays (usually caused by weekend or holiday hours), the family will always be informed of the status.

- Embalming and viewing are still possible after a cranial autopsy is performed. NPDPS staff members are available to consult with funeral homes to insure that families can still have their desired memorial services.
- Because of IRB regulations, results are reported to a clinician designated by the family. This facilitates answering questions and discussing any appropriate next steps with family members.
- If the autopsy shows that the patient does not have CJD, NPDPS can assist families who would like further evaluation and a final diagnosis.

To make autopsy arrangements, or for more information about the autopsy program, please contact our autopsy coordination team at 1-216-368-0587.

Thank you for helping us to further our understanding of this significant health concern.

Sincerely,

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