

Checklist for Healthcare Providers re Suspected CJD Cases

- Notify local or state public health department within 3 working days if CJD, variant CJD, or other TSE is suspected as a cause of the patient's illness. The local public health district can assist you with many of the following tasks.
- Discuss autopsy with patient and/or family.
- Determine who has authority over the remains (see Idaho Code Section 54-1142, <http://www3.state.id.us/cgi-bin/newidst?sctid=540110042.K>).
 - Possible referral to establish durable power of attorney for health care.
- Discuss genetic testing with patient and/or family.
 - Possible referral to a genetic counselor (see <http://www.nsgc.org/resourcelink.cfm>).
- Possible referral to CJD Foundation for family support, including help with making decisions on autopsy.
- Contact National Prion Disease Pathology Surveillance Center (NPDPSC), tel. 216-368-0587, <http://www.cjdsurveillance.com>. The NPDPSC coordinates all autopsies, performs all testing, and assists in making a diagnosis free of charge. For autopsy support after hours and on weekends, call the NPDPSC Autopsy Line at 216-647-8148 (this number should not be used for general inquiries)
- Complete NPDPSC forms, available on-line at <http://www.cjdsurveillance.com/forms.html>.
 - Autopsy consent form. (To be filled out by the family; 2 signature pages and 2 pages with patient information questions)
 - Test request form. (Must be filled out by the physician or lab sending tissue)
 - Testing and reporting form. (To be filled out by the physician; without it a final report providing an interpretation and possible diagnosis cannot be released)
- Provide contact for autopsy arrangements to NPDPSC.
- Provide clinical history of the patient to the NPDPSC.
 - Summary of medical information and progress notes since the date on onset
 - Information and results from EEGs and MRIs (on disk)
 - Summary of relevant family history
- Notification to funeral service director of precautions to take.

Miscellaneous Notes

- All testing and NPDPSC-approved autopsies are performed free of charge to the patient and the patient's family
- Autopsies should ideally be done within 72 hours of death; if this cannot be achieved than the body should be placed in refrigeration until the autopsy is performed
- Autopsies can be done at St. Alphonsus Regional Medical Center in Boise (contact NPDPSC to make arrangements)

See next page for CJD resources.

(over)

CJD Resources

National Prion Disease Pathology Surveillance Center, including protocols for specimen submission and testing: <http://www.cjdsurveillance.com/>.

World Health Organization information on prion disease diagnostics, patient care, clinical criteria, references, etc.: <http://www.who.int/bloodproducts/TSE-manual2003.pdf>.

Idaho Department of Health and Welfare information on CJD in Idaho: <http://www.diseaseinfo.idaho.gov>.

CJD Foundation, which provides support to families of CJD patients: <http://www.cjdfoundation.org/>.

American Red Cross blood donor eligibility: <http://www.redcross.org/en/eligibility#cid>

Genetic testing information: <http://www.genetests.org/>.

Centers for Disease Control and Prevention CJD website: <http://www.cdc.gov/ncidod/dvrd/cjd/>.