

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. To obtain the autopsy number please call the Office of Epidemiology & Food Protection at 208-334-5939 or call the NPDPSC at 216-368-0587.
- 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.

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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/>.