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Creutzfeldt-Jakob Disease (CJD) Resources

National Prion Disease Pathology Surveillance Center (Case Western Reserve University)

- Identify precise type of prion disease (sporadic, familial, or acquired) by examining histopathology, the prion protein type, and the prion protein gene
- · Monitor incidence of prion disease in the United States and for novel prion diseases
- Coordinate free brain-only autopsies through their national autopsy network and perform neuropathologic examination of brain tissue
- Analyze CSF (14-3-3 protein, t-Tau protein, and RT-QuIC), blood (genetic testing for familial CJD), and brain biopsy and autopsy tissue for suspected CJD cases
- RT-QuIC (real-time quaking-induced conversion): detects the abnormal prion protein
- Brain MRI interpretation service
- Website: http://www.cjdsurveillance.com or https://case.edu/medicine/pathology/divisions/prion-center
 - Testing and shipping information, protocols, forms, resources for families, resources for professionals, and autopsy coordination program information
- Phone: 216-368-0587: Fax: 216-368-4090
- Test Results Request Fax: 216-368-2546
- Autopsy Emergency Contact Information: 216-647-8148 (nights and weekends only)
- Email Address: cjdsurveillance@uhhospitals.org
- Address: 2085 Adelbert Rd Rm 419, Cleveland, Ohio 44106

CJD Foundation

- Support families affected by prion disease, raise awareness, and support medical education and research
- Website: https://cjdfoundation.org/
- Help Line: 1-800-659-1991
- Email Address: help@cjdfoundation.org

Centers for Disease Control and Prevention (CDC)

- CJD: https://www.cdc.gov/creutzfeldt-jakob/site.html
- CJD Diagnostic Criteria: https://www.cdc.gov/creutzfeldt-jakob/hcp/clinical-overview/diagnosis.html
- Infection Control: https://www.cdc.gov/creutzfeldt-jakob/hcp/infection-control/index.html
- Prion Diseases: https://www.cdc.gov/prions/about/index.html

World Health Organization (WHO)

- Infection Control Guidelines: https://apps.who.int/iris/handle/10665/66707
- Tissue Infectivity Tables: https://apps.who.int/iris/handle/10665/43498 (2006) and https://www.who.int/publications/m/item/WHO-EMP-QSM-2010.1 (2010 update)

Texas Department of State Health Services (DSHS)

- CJD Website: https://www.dshs.texas.gov/creutzfeldt-jakob-disease-cjd
- Phone: 512-776-7676Fax: 512-776-7616