

Creutzfeldt-Jakob Disease (CJD) Resources

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

- Provide free autopsies through their national autopsy network and brain tissue testing
- Provide CSF (14-3-3 protein, t-Tau protein, and RT-QuIC), blood (genetic testing for familial CJD), and brain biopsy and autopsy tissue testing for suspected CJD cases
 - RT-QuIC (real-time quaking-induced conversion): test to detect the abnormal prion protein
- Brain MRI interpretation service
- Establish precise type of prion disease (sporadic, familial, or acquired) by examining the prion protein and the prion protein gene
- Monitor occurrence of prion disease in the United States

Contact Information: 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

Website: <u>http://www.cjdsurveillance.com</u> or <u>https://case.edu/medicine/pathology/divisions/prion-</u> center

• Testing information, protocols, forms, resources for families, resources for professionals, and autopsy coordination program information

CJD Foundation

- Support families affected by prion disease
- Raise awareness
- Support medical education and research

Website: https://cjdfoundation.org/ Help Line: 1-800-659-1991

Centers for Disease Control and Prevention (CDC)

CJD: <u>https://www.cdc.gov/prions/cjd/index.html</u> CJD Diagnostic Criteria: <u>https://www.cdc.gov/prions/cjd/diagnostic-criteria.html</u> Infection Control: <u>https://www.cdc.gov/prions/cjd/infection-control.html</u> Prion Diseases: <u>https://www.cdc.gov/prions/</u>

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 updated 2010 tissue infectivity tables https://www.who.int/publications/m/item/WHO-EMP-QSM-2010.1#:~:text=lt%20is%20not%20the%20purpose%20of%20this%20document,materials%2C% 20and%20may%20have%20implications%20for%20future%20recommendations

Texas Department of State Health Services (DSHS)

CJD: <u>https://www.dshs.texas.gov/idcu/disease/creutzfeldt-jakob/</u> Phone: 512-776-7676 Fax: 512-776-7616