

CJD Resources

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

- Provide free autopsy through their national autopsy network and brain autopsy tissue testing
- Provide CSF (14-3-3 protein, t-Tau protein, and RT-QuIC), blood (genetic testing for familial CJD), and brain biopsy tissue testing on suspected CJD cases
 - RT-QuIC (real-time quaking-induced conversion): test to detect the abnormal prion protein
- 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; After Hours: (216) 647-8148

Test Results Request Fax: 216-368-2546

Address: 2085 Adelbert Rd Rm 419, Cleveland, Ohio 44106

Website: <http://www.cjdsurveillance.com>

- Testing information, protocols, forms, resources for families, resources for professionals

CJD Foundation

- Offer emotional support
- Educate about CJD
- Help families make decisions

Website: <https://cjdfoundation.org/>

24-Hour Help Line: 1-800-659-1991

Centers for Disease Control and Prevention (CDC)

CJD: <https://www.cdc.gov/prions/cjd/index.html>

CJD Diagnostic Criteria: <https://www.cdc.gov/prions/cjd/diagnostic-criteria.html>

Infection Control: <https://www.cdc.gov/prions/cjd/infection-control.html>

Prion Diseases: <https://www.cdc.gov/prions/>

World Health Organization

Infection Control Guidelines:

<https://www.who.int/csr/resources/publications/bse/whocdscsrgraph2003.pdf?ua=1> or

https://www.who.int/csr/resources/publications/bse/WHO_CDS_CSRAPH_2000_3/en/

International Case Definition:

<http://www.who.int/csr/resources/publications/surveillance/whocdscsrir992.pdf>

Texas Department of State Health Services

CJD: <https://www.dshs.texas.gov/idcu/disease/creutzfeldt-jakob/>

Phone: 512-776-7676

Fax: 512-776-7616