

Frequently Asked Questions Concerning Creutzfeldt-Jakob Disease (CJD)

Why was CJD made reportable?

Some states, including Idaho, made CJD and other prion diseases reportable recently to help monitor for variant CJD after Bovine Spongiform Encephalopathy (BSE, or "Mad Cow Disease") was detected in a cow in Washington State in December 2003. See <http://www.cdc.gov/ncidod/dvrd/bse/> for more information on BSE in the United States.

I want to report my relative's case of CJD to be sure it is investigated. Whom should I call?

If your relative is a resident of Idaho, ask the attending physician if the case has been reported to the health department in Idaho. In Idaho, physicians must report suspected or confirmed cases of CJD and other transmissible spongiform encephalopathies (prion diseases) to the health department.

If your relative is a resident of another state, contact the local or state health department in that state to find out if physicians are required to report CJD in that state. Not all states require physicians to report cases of CJD or other prion diseases. Links to your state health department can be found at <http://www.cdc.gov/mmwr/international/relres.html>.

Where can I get more information about CJD?

See the following links for information about CJD.

Centers for Disease Control and Prevention

<http://www.cdc.gov/ncidod/dvrd/cjd/>

National Library of Medicine and National Institutes of Health

<http://www.nlm.nih.gov/medlineplus/ency/article/000788.htm>

<http://ghr.nlm.nih.gov/condition=priondisease>

National Institute for Allergy and Infectious Disease

<http://www.niaid.nih.gov/publications/prion.htm>

The National Creutzfeldt-Jakob Disease Surveillance Unit (UK)

<http://www.cjd.ed.ac.uk/intro.htm>

World Health Organization

http://www.who.int/zoonoses/diseases/prion_diseases/en/

Medscape article on prion diseases (must register to view)

<http://www.medscape.com/viewarticle/410863>

Are there any support groups for families of CJD patients?

Yes. A listing of support groups can be found at

http://www.rarediseases.org/search/rdbdetail_abstract.html?disname=Creutzfeldt+Jakob+Disease

I'm learning that personal and family medical histories help physicians diagnose and treat their patients. What can I do to make sure that my doctor has my complete medical history?

You can develop your personal medical history and update it whenever there is a change.

You can also create a medical family tree. The following links provide information on how to create your own health record and how to make a medical family tree.

E-medicine Consumer Health

Family medical records

<http://www.emedicinehealth.com/articles/11909-1.asp>

American Association of Family Practitioners

Creating a Health Journal

<http://www.familydoctor.org/838.xml>

The Mayo Clinic

How to compile your family medical history

<http://www.mayoclinic.com/invoke.cfm?id=HQ01707>