



CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

Supporting Families Affected by Prion Disease



WHO WE ARE

WHAT IS THE CREUTZFELDT-JAKOB DISEASE FOUNDATION?

Mission and Vision

The Creutzfeldt-Jakob Disease Foundation, Inc. is a registered not-for-profit foundation.

Our mission is to:

- Provide education and support to families affected by prion diseases including CJD
- Educate medical, hospice, and funeral professionals about CJD and the care of CJD patients
- Raise awareness of CJD
- Support research aimed at finding a treatment and a cure

Services We Provide

- HelpLine support and education to families, caregivers, healthcare professionals, and the public
- Physician referral
- Medical education
- Information about caregiving for CJD patients
- Annual CJD Foundation Family Conference in Washington, D.C., family workshops around the country, and monthly teleconferences with expert speakers
- Educational DVDs for healthcare and funeral professionals
- Website: www.cjdfoundation.org
- Research grants to support the understanding of prion disease and pursuit of treatments and a cure

CJD CAN BE CHALLENGING TO DIAGNOSE, AND IS DEVASTATING TO THE PATIENT AND FAMILY.

WE ARE HERE TO HELP YOU WITH FACTS, REFERRALS, CONNECTIONS, AND INFORMATION ABOUT PROGRAMS TO ASSIST YOU.

Information We Provide

- Prion diseases—the different forms and diagnostic issues
- How to care for a family member with CJD
- How to care for yourself during this difficult time
- How to identify and participate in research studies
- Referrals to doctors with CJD expertise
- Science-based information about infection control and funeral issues
- Current research updates

Our Contact Information

HelpLine: 1.800.659.1991

HelpLine Email: help@cjdfoundation.org

Website: www.cjdfoundation.org

We are available to help you with questions and concerns Monday through Friday, 9 am to 5 pm ET. Messages left on our voicemail after hours concerning patients will be returned evenings and weekends.

WHAT IS CREUTZFELDT-JAKOB DISEASE?

Creutzfeldt-Jakob Disease, CJD, is a rare and fatal neurological disease. For in-depth information about CJD, please visit www.cjdfoundation.org.

CJD Facts

- CJD is the cause of 1/6,000-1/10,000 deaths in the USA every year
- The mean duration of CJD from onset of symptoms until death is 4-6 months with the majority of patients passing within one year.
- CJD is often characterized by a rapidly progressive dementia and is sometimes misdiagnosed as other diseases such as Alzheimer's disease

Tests That Support a Clinical Diagnosis of Probable CJD

- History and physical examination
- An appropriate work-up that rules out other possible diagnoses
- Cerebrospinal fluid (CSF) Test (spinal tap) for:
 - Real-Time Quaking Induced Conversion (RT-QuIC), which detects prion activity
 - Markers of brain cell injury: 14-3-3 and tau proteins
- Brain MRI – specifically DWI/FLAIR sequences
- Electroencephalogram (EEG)
- Genetic testing of the prion protein gene to determine if it is genetic or not
- A post-mortem examination of the brain tissue (autopsy)



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CJD FOUNDATION TOLL-FREE HELPLINE

1.800.659.1991
help@cjd.foundation.org

The **HelpLine** is staffed by knowledgeable individuals who have had first-hand experience with CJD. Patients, family members, medical professionals, funeral professionals and others are encouraged to call us with questions about:

- A suspected or confirmed CJD diagnosis
- Hospice care
- Patient care
- Family support
- Autopsy
- Research
- Funeral arrangements
- Participation in our questionnaire
- Our educational DVDs for medical and funeral professionals
- Surveillance
- Political and public advocacy
- Donations
- General CJD Information

SUPPORTING THE CJD FOUNDATION

To support the work of the CJD Foundation, you may donate online or by phone with Visa, MasterCard or Amex. You may also donate by downloading a form from www.cjd.foundation.org/donate and faxing or mailing it to:

The CJD Foundation
3634 W. Market Street, Suite 110
Akron, Ohio 44333

Phone: 800.659.1991
Fax: 234.466.7077

Please make checks payable to the CJD Foundation. Thank you for supporting this vital mission!

THE CJD FOUNDATION

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