Patient Questionnaire

Surveillance of Creutzfeldt-Jakob Disease (CJD) is of critical importance in our country. However, CJD surveillance is in great need of improvement concerning the detailed patient information that only family members can fully provide. Therefore, to fill this gap, the CJD Foundation in collaboration with the National Prion Disease Pathology Surveillance Center has compiled the following questionnaire. We hope you agree that the availability of detailed information is critical for the accurate evaluation of each case and that you will complete this questionnaire. Your input will greatly assist us in maintaining an accurate database for CJD cases, providing valuable information to more accurately classify prion diseases and further research, building a family network of support, and continuing our organized efforts to meet all of the issues surrounding CJD. The information you provide will be permanently added to our database.

In completing this questionnaire, I hereby give consent to the CJD Foundation to use this information solely in connection with activities related to promoting the research of CJD and other prion diseases. I also give consent to the CJD Foundation to share the information provided with the National Prion Disease Pathology Surveillance Center. Further, I understand that the information I am providing will not be sold or used at any time for commercial purposes. The consent form and questionnaire will be filed with the CJD Foundation. This consent form is to be signed by the questionnaire participant and returned along with the questionnaire to:

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

For your convenience, a stamped addressed envelope is enclosed to return the completed questionnaire.

Today's Date: ___________________________

Name of Patient: ____

Printed Name of Person(s) Filling Out Questionnaire:____

Your Signature: ____

Participant's Contact Information

Your relationship to the patient:

- ☐ Husband
- ☐ Wife
- ☐ Significant other
- ☐ Son
- ☐ Daughter
- ☐ Mother
- ☐ Father
- ☐ Sister
- ☐ Brother
- ☐ Friend
- ☐ Extended family member (please specify): ____
- ☐ Other (please specify): ____

Street Address: ____

City: ______________________________ **State:** ____________ **Zip:** ______________

Phone Number: ____

Email Address: ____

Would you like to receive (or continue receiving) updates from the CJD Foundation? ☐ Yes ☐ No

General Patient Information

Patient Name: ____

Sex: ☐ Male ☐ Female **Age at death:** ____________

Date of birth: ________________________ **Date of death:** ___________________________

Birthplace: ____

Location where symptoms began (city, state): ___________________________________

Location where patient died (city, state): _____________________________________

Other residential history (where and what years): _______________________________

____

____

____

____

What type of insurance did your loved one have:

- ☐ Private insurance
- ☐ Medicare
- ☐ Medicaid
- ☐ Veteran/Military Benefits
- ☐ None
- ☐ Other: please specify: ____

Was Creutzfeldt-Jakob Disease/CJD listed on the patient's death certificate?

- ☐ Yes
- ☐ No
- ☐ Unknown

How was CJD listed on the death certificate?

- ☐ Immediate cause (listed 1st)
- ☐ Underlying cause (listed 2nd, 3rd or 4th)
- ☐ N/A – not listed on the death certificate

Ethnic Origin (check all that apply):

- ☐ Caucasian (White/Non-Hispanic)
- ☐ Hispanic/Latino
- ☐ African American
- ☐ Native American
- ☐ Asian
- ☐ Other – please specify: ____

Marital Status:

- ☐ Single
- ☐ Married
- ☐ Divorced
- ☐ Widowed
- ☐ Lived with significant other

Number of children:

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 or more – specify the exact number: _____________

Education:

- ☐ Did not graduate from High School or receive GED
- ☐ GED
- ☐ High School Graduate
- ☐ Vocational/Trade School
- ☐ Some College
- ☐ College Graduate
- ☐ Graduate School

CJD Diagnosis Information

Duration of illness: (Check ONE)

- ☐ Less than 3 months
- ☐ 3-6 months
- ☐ 7-12 months
- ☐ 13-18 months
- ☐ 19-24 months
- ☐ More than 24 months
- ☐ Unknown

Initial symptoms (check all that apply):

- ☐ Dementia *(memory impairment, confusion)*
- ☐ Visual disturbances *(blindness, blurry vision, double vision, impaired depth or color perception, etc.)*
- ☐ Hallucinations
- ☐ Ataxia *(impaired balance and/or gait, etc.)*
- ☐ Sleep problems *(fatigue, insomnia, etc.)*
- ☐ Speech impairment
- ☐ Weakness
- ☐ Psychiatric disturbances *(depression, anxiety, unusual anger, irrational fears, personality changes, etc.)*
- ☐ Numbness or tingling
- ☐ Weight loss
- ☐ Jerking movements, seizures, and/or tremors
- ☐ Other initial symptom(s) - please specify*:* ____
- ☐ Unknown

Did the patient experience any unusual stress one year or less prior to the onset of symptoms (surgery, trauma, death of a loved one, difficult personal situation, etc.) ☐ Yes ☐ No ☐ Unknown

If yes, please *briefly* explain: ____

____

Did the patient develop a dry, annoying cough one year or less prior to the onset of symptoms?

☐ Yes ☐ No ☐ Unknown

Did the patient have flu-like symptoms one year or less prior to the onset of symptoms?

☐ Yes ☐ No ☐ Unknown

What types of tests/procedures were conducted during the diagnostic process? (check all that apply):

- ☐ EEG
- ☐ MRI
- ☐ Spinal Tap
- ☐ Clinical Observation
- ☐ Brain Biopsy (tissue examination while the patient is living): Result: ____
- ☐ Other – please specify: ____
- ☐ Unknown

Information about the Spinal Fluid Testing:

Was the Real-Time Quaking Induced Conversion (RT-QuIC) test run in the spinal fluid (CSF)?

☐ Yes ☐ No ☐ Unknown

If yes, what was the result? ☐ Positive ☐ Negative ☐ Inconclusive ☐ Unknown

Was the spinal fluid (CSF) tested for 14-3-3 protein? ☐ Yes ☐ No ☐ Unknown

If yes, what was the result? ☐ Positive ☐ Negative ☐ Inconclusive ☐ Unknown

Was the spinal fluid (CSF) tested for Tau elevation? ☐ Yes ☐ No ☐ Unknown

If yes, what was the elevation number? ______________________ ☐ Unknown

Information about the Physician(s) who made the initial CJD diagnosis:

Name(s): ____

Specialty:

- ☐ Neurologist
- ☐ General Practitioner
- ☐ Ophthalmologist
- ☐ Psychiatrist
- ☐ Unknown
- ☐ Other – please specify: ____

Name of the Medical Center/Facility where the physician made the initial CJD diagnosis:

____

Address: ____

Phone Number: ____

Would you recommend this physician to another family? ☐ Yes ☐ No

**The CJD Foundation uses the physicians you recommend as referrals for future families affected by CJD in your area.*

Did you feel the diagnosing physician was compassionate? ☐ Yes ☐ No ☐ Unknown

Was the physician well informed about:

- **CJD?** ☐ Yes ☐ No ☐ Unknown
- **The CJD Foundation?** ☐ Yes ☐ No ☐ Unknown
- **The National Prion Disease Pathology Surveillance Center's (NPDPSC) autopsy services?**
  ☐ Yes ☐ No ☐ Unknown

Did the physician use the term "Mad Cow Disease" to describe the patient's illness?

☐ Yes ☐ No ☐ Unknown

If yes, please explain: ____

____

Did the physician continue to be helpful and available after the diagnosis was made?

☐ Yes ☐ No ☐ Unknown

Autopsy Information

Was an autopsy performed? ☐ Yes ☐ No ☐ Unknown

If not, why (check all that apply)?

☐ Family refused
☐ Religious reasons
☐ Brain biopsy was performed, did not want an autopsy
☐ Never suggested or discussed
☐ Could not find someone to perform the autopsy
☐ Unknown
☐ Other – please specify: ____

If an autopsy was performed, who arranged it? (check all that apply)

☐ The CJD Foundation and NPDPSC
☐ NPDPSC
☐ Hospice
☐ Physician
☐ Hospital
☐ Health Department
☐ Medical Examiner
☐ Funeral Home
☐ Unknown
☐ Other (please specify): ______________________________

If you answered NPDPSC to the question above, who referred you to NPDPSC?

☐ CJD Foundation
☐ Physician
☐ Hospice
☐ Health Department
☐ Medical Examiner
☐ Funeral Home
☐ Unknown
☐ Other (please specify): ______________________________________

Was this case referred to any other research facilities? ☐ Yes ☐ No ☐ Unknown
If yes, which one? ____

At what type of Medical Center/Facility was the autopsy performed?

- ☐ Hospital
- ☐ Funeral Home
- ☐ Medical Examiner's Facility
- ☐ Unknown
- ☐ Other – please specify: ____

Did the autopsy confirm CJD or any other prion disease?

- ☐ Yes
- ☐ No
- ☐ Inconclusive results
- ☐ Results Pending
- ☐ Unknown

If yes, what specific type of CJD/prion disease was confirmed?

- ☐ Sporadic
- ☐ Familial (hereditary)
- ☐ Iatrogenic (acquired)
- ☐ Variant
- ☐ Gerstmann-Straussler-Scheinker Syndrome (GSS)
- ☐ Fatal Familial Insomnia (FFI)
- ☐ Sporadic Fatal Insomnia
- ☐ PSPr
- ☐ Final Report is Pending
- ☐ Unknown
- ☐ Other (please specify): ____

Patient Background & Family History

Number of siblings:

- ☐ 0 – Patient was an only child
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ More than 6 (please specify the exact number): _____________

Is there any family history of neurological conditions, including CJD, another prion disease, or a brain disease associated with mental deterioration? ☐ Yes ☐ No ☐ Unknown

If yes, please check the all neurological/mental condition(s) that apply.

- ☐ CJD or other Prion Disease
- ☐ Multiple Sclerosis
- ☐ Alzheimer's Disease
- ☐ Parkinson's Disease
- ☐ Hashimoto's Disorder
- ☐ Lewy Body Disease
- ☐ Pick's Disease
- ☐ Stroke
- ☐ Brain tumor
- ☐ Bipolar disorder
- ☐ Other – please specify: ______________________________

If you checked any of the conditions above, please provide the following information:

Relationship	*Neurological/Mental Condition*	*Year of death*	*Age at death*	*Autopsy performed?*

Patient's primary occupation(s) during the last 10 yrs: ______________________________

Did the patient ever work in the following areas (If yes, provide brief details in the space provided):

- ☐ Medical (physician, nurse, dentist, etc.) ______________________________
- ☐ Animal farming ______________________________
- ☐ Animal laboratories ______________________________
- ☐ Meat industry ______________________________
- ☐ Veterinary medicine ______________________________
- ☐ Research laboratories ______________________________
- ☐ Pharmaceutical laboratories ______________________________
- ☐ Chemical laboratories ______________________________
- ☐ None of the above
- ☐ Unknown

Food Consumption & Animal Exposure

Did the patient eat BEEF? ☐ Frequently ☐ Occasionally ☐ Rarely ☐ Never

Did the patient eat DEER and/or ELK? ☐ Frequently ☐ Occasionally ☐ Rarely ☐ Never

If yes, was the deer and/or elk from the wild? ☐ Yes ☐ No ☐ Unknown

Did the patient ever consume the following animal parts (please specify the type of animal in the space provided):

- ☐ Brains ____
- ☐ Spinal Cord ____
- ☐ Eyes ____
- ☐ Other organs – please specify: ____
- ☐ Unknown
- ☐ Not applicable - patient did not consume any of the above

Was the patient a Vegetarian? ☐ Yes ☐ No ☐ Unknown

If yes, approximately what years? (e.g. 1981-2007) ________________________________

Did the patient work or live on a farm? ☐ Yes ☐ No ☐ Unknown

If yes, did they have any exposure to or engage in activities involving the following animals (check all that apply):

- ☐ Cattle
- ☐ Pigs
- ☐ Sheep
- ☐ Chickens
- ☐ Mink
- ☐ Not applicable – patient did not work or live on a farm.

Travel

Did the patient travel outside of the U.S. (including any military service) during *1980-1999* ?

☐ Yes ☐ No ☐ Unknown

If yes, please check the appropriate location(s) and specify the duration:

- ☐ **United Kingdom** *☐ 1 week ☐ 1 month ☐ 1-3 months ☐ 3-6 months ☐ More than 6 months*
- ☐ **Japan** *☐ 1 week ☐ 1 month ☐ 1-3 months ☐ 3-6 months ☐ More than 6 months*
- ☐ **Eastern Europe** *☐ 1 week ☐ 1 month ☐ 1-3 months ☐ 3-6 months ☐ More than 6 months*
- ☐ **France** *☐ 1 week ☐ 1 month ☐ 1-3 months ☐ 3-6 months ☐ More than 6 months*
- ☐ **Canada** *☐ 1 week ☐ 1 month ☐ 1-3 months ☐ 3-6 months ☐ More than 6 months*

☐ **Other – please specify location and duration:**

____

____

Medical History

Patient's general health (choose ONE):

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

Prior medical conditions:

____

____

____

____

Medications used prior to the onset of CJD symptoms, including any extended course of antibiotics and/or steriods (if possible, please name the medication, what it was used to treat and the dates it was used):

____

____

____

____

Did the patient take doxycycline? ☐ Yes ☐ No ☐ Unknown

If yes, what dosage? ☐ 100mg ☐ Other

If yes, for how long?

- ☐ Less than 3 months
- ☐ 3-5 months
- ☐ 6-8 months
- ☐ 9-12 months
- ☐ More than 12 months
- ☐ Unknown

Did the patient take any vitamins and/or supplements? ☐ Yes ☐ No ☐ Unknown
If yes, list below:

____

____

Surgeries:

Please list all surgeries, types, and year. Please include those known surgeries occurring over at least the last 35 years and indicate whether a blood transfusion was received for that surgery by writing in Yes, No, or Don't Know. If you need more room, please attach another page.

Type of surgery:	*Date:*	*Institution/ Location:*	*Blood Transfusion*
Example: Gall Bladder Removed	*June 2001*	*Emory Hosp. Atlanta, GA*	*No*

Did the patient ever receive a blood transfusion before the onset of the current neurological illness?

- ☐ Yes
- ☐ No
- ☐ Don't Know

If yes, what is your best estimate of the time period before the onset of the patient's current neurological illness during which one or more blood transfusions were received (please check the appropriate box or boxes below).

- ☐ Less than 5 years before the onset
- ☐ 5-9 years before the onset
- ☐ 10-14 years before the onset
- ☐ 15-19 years before the onset
- ☐ 20-24 years before the onset
- ☐ 25-29 years before the onset
- ☐ 30-34 years before the onset
- ☐ 35-39 years before the onset
- ☐ 40+ years before the onset

Did the patient ever receive a tissue or organ transplant?

If yes, check the appropriate box(s) below and provide the date, institution and location the transplant was performed in the space provided:

- ☐ Liver: ______________________________
- ☐ Kidney: ______________________________
- ☐ Bone marrow: ______________________________
- ☐ Corneal: ______________________________
- ☐ Other (please specify): ______________________________
- ☐ Not applicable – no tissue or organ transplants

Did the patient have any of the following medical procedures performed (other than surgeries)?

- ☐ Gastric
- ☐ Endoscopy
- ☐ Colonoscopy
- ☐ Other – please specify: ____
- ☐ Not applicable – no medical procedures

Did the patient ever have a spinal tap (*<u>other than any spinal tap(s) performed to help diagnosis CJD</u>*), or any procedure in which a needle was inserted into the spine? ☐ Yes ☐ No ☐ Unknown

If yes:

Date: ____________________________

Institution/Location: ____

Did the patient have any medical condition(s) associated with the thyroid?

☐ Yes ☐ No ☐ Unknown

If yes, please explain: ____

Was the patient ever a blood donor? ☐ Yes ☐ No ☐ Unknown

**Please see the enclosed request from the American Red Cross* (*marked with a leading asterisk*)

Did patient ever have a transfusion of albumin or immunoglobulin? ☐ Yes ☐ No ☐ Unknown

If yes:

Date: ____________________________

Institution/Location: ____

Did the patient ever have any dental surgery(s) such as extractions or root canals?

☐ Yes ☐ No ☐ Unknown

If yes:

Surgery/procedure performed: ____

Date: ____________________________

Institution/Location: ____

Did the patient ever have any eye surgery(s), including cataract surgery? ☐ Yes ☐ No ☐ Unknown

If yes:

Surgery/procedure performed: ____

Date: ____________________________

Institution/Location: ____

Did the patient use contact lenses? ☐ Yes ☐ No ☐ Unknown

Did the patient use eye drops? ☐ Yes ☐ No ☐ Unknown

Did the patient ever receive HGH treatment (human growth hormone)? ☐ Yes ☐ No ☐ Unknown

If yes:

Date: ____________________________

Institution/Location: ____

Did patient receive any hormone replacement therapy? ☐ Yes ☐ No ☐ Unknown

If yes, please specify including the name of the drug: ____

Did the patient receive any homeopathic/herbal therapy: ☐ Yes ☐ No ☐ Unknown

If yes, please specify: ____

Was the patient Diabetic? ☐ Yes ☐ No ☐ Unknown

If yes, what type? _________________

Did the patient use insulin? ☐ Yes ☐ No ☐ Unknown

If yes, what type? ____

Was the patient's diabetes diet controlled *only*? ☐ Yes ☐ No ☐ Unknown

Did the patient have any vaccinations or injections including any treatment involving a course of injections?

(do not include childhood vaccinations) ☐ Yes ☐ No ☐ Unknown

If yes, specify the purpose and the approximate year(s):

____

Did the patient ever use intravenous (IV) drugs? ☐ Yes ☐ No ☐ Unknown

Did the patient ever have acupuncture? ☐ Yes ☐ No ☐ Unknown

Did the patient have any tattoos? ☐ Yes ☐ No ☐ Unknown

Did the patient have any piercings (ears, other body parts)? ☐ Yes ☐ No ☐ Unknown

Additional Information

Is there any other information you feel should be noted about the patient? (i.e. personality traits, hobbies and activities, memberships or affiliations, unusual habits or routine activities, environmental concerns, etc.)

Where did you find information / support?

Please use the space below to note any concerns you may wish to share with the CJD Foundation: