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): ____________________________

Patient Name:
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
□ PSp
□ 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): ____________

Patient Name:  7
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:

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Neurological/Mental Condition</th>
<th>Year of death</th>
<th>Age at death</th>
<th>Autopsy performed?</th>
</tr>
</thead>
<tbody>
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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:
________________________________________________________________________
________________________________________________________________________

Patient Name:
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 steroids (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.

<table>
<thead>
<tr>
<th>Type of surgery</th>
<th>Date</th>
<th>Institution/ Location</th>
<th>Blood Transfusion</th>
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</thead>
<tbody>
<tr>
<td>Example: Gall Bladder Removed</td>
<td>June 2001</td>
<td>Emory Hosp. Atlanta, GA</td>
<td>No</td>
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### 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 (other than any spinal tap(s) performed to help diagnosis CJD), 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

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.)

________________________________________________________________________________
________________________________________________________________________________
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Where did you find information / support?
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

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

Patient Name: