**ATTENTION Local Health Department Staff:** There is no Part 2 Wizard for this disease. Enter all information from this form into the NC EDSS question packages.

If sending this form to the Health Care Provider, remember to attach a cover letter from your agency indicating the part(s) of the form the provider should complete.

### CLINICAL FINDINGS

<table>
<thead>
<tr>
<th>Is/was patient symptomatic for this disease?</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, symptom onset date (mm/dd/yyyy)</td>
<td>/ /</td>
<td>/ /</td>
<td>/ /</td>
</tr>
<tr>
<td>Fever</td>
<td>Yes, subjective</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Yes, measured</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Highest measured temperature</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fever onset date (mm/dd/yyyy)</td>
<td>/ /</td>
<td></td>
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<tr>
<td></td>
<td>Altered mental status</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Patient displayed (select all that apply)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxiety/apprehension</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Coma</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hallucinations</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychiatric / behavioral problems</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Memory loss</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Muteness</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Aphasia</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Apraxia</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Ataxia</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Gait disturbance</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Dyscoordination</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Myoclonus</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Tremor</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Nystagmus</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Cortical blindness</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Spasticity</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Babinski's sign</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Inosimila</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Cranial nerve or bulbar weakness</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>or paralysis</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>or difficulty speaking</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Other, specify</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

**Head CT performed** | Y | N | U |
| Date performed (mm/dd/yyyy) | / / |
| **MRI performed** | Y | N | U |
| Date performed (mm/dd/yyyy) | / / |
| **Bilateral pulvinar high signal** | Y | N | U |
| **Positive 14-3-3 CSF assay** | Y | N | U |
| If yes, give details: | |
| **Brain biopsy** | Y | N | U |
| If yes, give details: | |
| **Tongue biopsy** | Y | N | U |
| If yes, give details: | |
| **Immunocytochemical testing** | Y | N | U |
| If yes, give details: | |
| **Western blot confirmed protease-resistant PrP** | Y | N | U |
| If yes, give details: | |
| **Scrapie associated fibrils** | Y | N | U |
| If yes, give details: | |

### CLINICAL OUTCOMES

| Discharge/Final diagnosis: | Y | N | U |
| Died? | Y | N | U |
| Died from this illness? | Y | N | U |
| Date of death (mm/dd/yyyy): | / / |
| **Autopsy performed?** | Y | N | U |
| If yes, provide details: | |

**Immuno-**

**If yes, was abnormal protease resistant PrP present?** | Y | N | U |
| **Additional details:** | |
| **Prion protein (PrP) gene sequencing?** | Y | N | U |
| If yes, provide details: | |

**Source of death information (select all that apply):**

- Death certificate
- Autopsy report final conclusions
- Hospital/discharge physician summary
- Other

**Immunostaining with 3F4 monoclonal antibody?** | Y | N | U |
| **If yes, were granular deposits seen?** | Y | N | U |

**Location of autopsy:**

- Autopsied outside NC, specify where:

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**Note:**

Enter all information from this form into the NC EDSS question packages. If sending this form to the Health Care Provider, remember to attach a cover letter from your agency indicating the part(s) of the form the provider should complete.
**HOSPITALIZATION INFORMATION**

Was patient hospitalized for this illness >24 hours? □ Y □ N □ U

Hospital name: ___________________________

City, State: ___________________________

Hospital contact name: ___________________________

Telephone: (______) ______ - ___________

Admit date (mm/dd/yyyy): ____/____/____

Discharge date (mm/dd/yyyy): ____/____/____

**OTHER EXPOSURE INFORMATION**

Has the patient ever served in the U.S. military? □ Y □ N □ U
If yes, dates of service:

From / ______ to / ______

During the 30 years prior to onset of symptoms, did the patient work in any of the following occupations or settings? (check all that apply):

☐ Health care worker
☐ Other sensitive occupation or setting
☐ Unknown

Nature of work/contact: __________________________________________

Name of facility: __________________________________________

Address: __________________________________________

City: __________________________________________

State: ___________ Zip: ___________

Telephone: (______) ______ - ___________

**ISOLATION/QUARANTINE/CONTROL MEASURES**

Restrictions to movement or freedom of action? □ Y □ N □ U

Specify __________________________

Did local health director or designee implement additional control measures (eg: precautions, notifications to funeral home, medical examiner, etc.)? □ Y □ N □ U

If yes, specify: __________________________________________

Were written isolation orders issued? □ Y □ N □ U

If yes, where was the patient isolated? __________________________________________

**HEALTH CARE FACILITY AND BLOOD & BODY FLUID EXPOSURE RISKS**

During the 30 years prior to onset of symptoms, did the patient have any of the following health care exposures?

**Blood or blood products (transfusion) recipient** □ Y □ N □ U

Date received (mm/dd/yyyy): ____/____/____

Was date before 1992? □ Y □ N □ U

Facility name
City: ___________________________
State: ___________________________
Country: ___________________________

**Human pituitary growth hormone recipient** □ Y □ N □ U

Date last administered (mm/dd/yyyy): ____/____/____

Provider name
Facility name
City: ___________________________
State: ___________________________
Country: ___________________________

Specify frequency and length of time that human pituitary growth hormone was administered:

**Surgery (besides oral surgery), obstetrical or invasive procedure** □ Y □ N □ U

**Admission date (mm/dd/yyyy): ____/____/____**

**Type of procedure**
Provider name
Facility name
City: ___________________________
State: ___________________________
Country: ___________________________

Was facility notified regarding ill patient? □ Y □ N □ U □ N/A

Name of person notified
Date notified (mm/dd/yyyy): ____/____/____

**Transplant recipient (tissue/organ/bone/ bone marrow, corneal graft, dura mater graft, or other tissue)** □ Y □ N □ U

If yes, specify type:

**Date received (mm/dd/yyyy): ____/____/____**

Was date before 1992? □ Y □ N □ U

Facility name
City: ___________________________
State: ___________________________
Country: ___________________________

**TRAVEL & IMMIGRATION**

Patient is: □ Resident of NC
□ Resident of another state or US territory
□ Foreign Visitor
□ Refugee
□ Recent Immigrant
□ Foreign Adoptee
□ None of the above

**Did patient have a travel history to the UK, Europe, or the Middle East during the 30 years prior to onset of symptoms?** □ Y □ N □ U

List travel dates and destinations:

From ____/____/____ to ____/____/____

**Does patient know anyone else with similar symptom(s) who had the same or similar travel history?** □ Y □ N □ U

List persons and contact information:

_________________________________________

_________________________________________

**GEOGRAPHICAL SITE OF EXPOSURE**

In what geographical location was the patient most likely exposed?

□ In NC
□ City ___________________________
□ County ___________________________
□ Outside NC, but within US
□ City ___________________________
□ State ___________________________
□ County ___________________________
□ Outside US
□ City ___________________________
□ Country ___________________________
□ Unknown ___________________________

Is the patient part of an outbreak of this disease? □ Y □ N

Notes:

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**CASE INTERVIEW**

Was the patient interviewed? □ Y □ N □ U

Date of interview (mm/dd/yyyy): ____/____/____

Were interviews conducted with others? □ Y □ N □ U

Who was interviewed?

Were health care providers consulted? □ Y □ N □ U

Who was consulted?

Medical records reviewed (including telephone review with provider/office staff)? □ Y □ N □ U

Specify reason if medical records were not reviewed:

Notes on medical record verification: __________________________

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DHHS/EPI #66

JANUARY 2009

CREUTZFELDT-JAKOB DISEASE

PAGE 2 OF 3
Creutzfeldt-Jakob Disease (CJD)

2007 Case Definition (North Carolina)

1. Sporadic CJD
   - **Confirmed:**
     A person who had clinically compatible illness diagnosed by one or more of the following:
     - Standard neuropathological techniques
     - Immunocytochemically
     - Western blot confirmed protease-resistant PrP
     - Presence of scrapie-associated fibrils
   - **Probable:**
     A person with progressive dementia and at least two of the following four clinical features:
     - Myoclonus
     - Visual or cerebellar signs
     - Pyramidal/extrapyramidal signs
     - Akinetic mutism
     - Typical EEG during an illness of any duration, or
     - Positive 14-3-3 CSF assay plus a clinical duration to death of <2 years
     - Routine investigation does not suggest an alternative diagnosis
   - **Suspect:**
     A person with progressive dementia and at least two of the following four clinical features:
     - Myoclonus
     - Visual or cerebellar signs
     - Pyramidal/extrapyramidal signs
     - Akinetic mutism
     - No EEG or an atypical EEG
     - Duration to death of <2 years

2. Iatrogenic CJD
   - A person with progressive cerebellar syndrome with a history of receiving human cadaveric-derived pituitary hormone, or
   - A person with sporadic CJD with history of a recognized exposure risk such as antecedent neurosurgery with dura mater implantation

3. Familial CJD
   - A person with confirmed or probable CJD who has a first degree relative with a history of either:
     - Confirmed or probable CJD, or
     - Neuropsychiatric disorder and disease-specific PrP gene mutation.