North Carolina Department of Health and Human Services
Division of Public Health • Epidemiology Section
Communicable Disease Branch

North Carolina Public Health

ATTENTION HEALTH CARE PROVIDERS:
Please report relevant clinical findings about this disease event to the local health department.

CREUTZFELDT-JAKOB DISEASE
Confidential Communicable Disease Report—Part 2
NC DISEASE CODE: 66

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.

Patient's Last Name	First	Middle	Suffix	Maiden/Other	Alias	Birthdate *(mm/dd/yyyy)* / /
						SSN

NC EDSS LAB RESULTS Verify if lab results for this event are in NC EDSS. If not present, enter results.

Specimen Date	Specimen #	Specimen Source	Type of Test	Test Result(s)	Description (comments)	Result Date	Lab Name—City/State
/ /						/ /	
/ /						/ /	
/ /						/ /	

CLINICAL FINDINGS

Is/was patient symptomatic for this disease? ☐Y ☐N ☐U
If yes, symptom onset date (mm/dd/yyyy): __/__/____
Fever ☐Y ☐N ☐U
☐ Yes, subjective ☐ No
☐ Yes, measured ☐ Unknown
Highest measured temperature_____
Fever onset date (mm/dd/yyyy):____/____/____
Altered mental status ☐Y ☐N ☐U
Patient displayed (select all that apply)
☐ Confusion ☐ Anxiety/apprehension
☐ Dementia ☐ Depression
☐ Coma ☐ Hallucinations
Psychiatric / behavioral problems ☐Y ☐N ☐U
Memory loss ☐Y ☐N ☐U
Muteness ☐Y ☐N ☐U
Aphasia ☐Y ☐N ☐U
Apraxia ☐Y ☐N ☐U
Ataxia ☐Y ☐N ☐U
Gait disturbance ☐Y ☐N ☐U
Dyscoordination ☐Y ☐N ☐U
Myoclonus ☐Y ☐N ☐U
Tremor ☐Y ☐N ☐U
Nystagmus ☐Y ☐N ☐U
Cortical blindness ☐Y ☐N ☐U
Spasticity ☐Y ☐N ☐U
Babinski's sign ☐Y ☐N ☐U
Insomnia ☐Y ☐N ☐U
Cranial nerve or bulbar weakness or paralysis ☐Y ☐N ☐U
☐ Difficulty speaking
☐ Other, specify_____
EEG performed ☐Y ☐N ☐U
Date performed (mm/dd/yyyy): ____/____/____
Result _____
Official interpretation of EEG consistent with CJD ☐Y ☐N ☐U

Head CT performed ☐Y ☐N ☐U
Date performed (mm/dd/yyyy):____/____/____
Result:_____
MRI performed ☐Y ☐N ☐U
Date performed (mm/dd/yyyy):____/____/____
Result:_____
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-resisted PrP? ☐Y ☐N ☐U
If yes, give details: _____
Scrapie associated fibrils? ☐Y ☐N ☐U
If yes, give details: _____

CLINICAL OUTCOMES

Discharge/Final diagnosis:_____
_____
Survived? ☐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
Patient autopsied in NC? ☐Y ☐N ☐U
County of autopsy:_____
Autopsied outside NC, specify where:_____
Source of death information (select all that apply):
☐ Death certificate
☐ Autopsy report final conclusions
☐ Hospital/discharge physician summary
☐ Other
Immunocytotesting? ☐Y ☐N ☐U
Immunoblot, western blot? ☐Y ☐N ☐U
If yes, was abnormal protease resistant PrP present? ☐Y ☐N ☐U
Additional details:
Immunostaining with 3F4 monoclonal antibody? ☐Y ☐N ☐U
If yes, were granular deposits seen? ☐Y ☐N ☐U
Prion protein (PrP) gene sequencing? ☐Y ☐N ☐U
If yes, provide details:
(? sporadic CJD, including genotype or other classification)

Patient's Last Name	First	Middle	Suffix	Maiden/Other	Alias	Birthdate *(mm/dd/yyyy)* / /
						SSN

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):____/____/____

ISOLATION/QUARANTINE/CONTROL MEASURES

Restrictions to movement or freedom of action? ☐Y ☐N
Specify _____
Did local health director or designee implement additional control measures (eg: precautions/ notifications to funeral home, medical examiner, etc.? ☐Y ☐N
If yes, specify: _____
_____
Were written isolation orders issued? ☐Y ☐N
If yes, where was the patient isolated? _____
_____

TRAVEL & IMMIGRATION

The 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:
_____
_____
_____

Additional travel/residency information:

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: (_____) _____

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 _____

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:

GEOGRAPHICAL SITE OF EXPOSURE

In what geographic location was the patient MOST LIKELY exposed?
Specify location:
☐ 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:

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

and

- Typical EEG during an illness of any duration, **or**
- Positive 14-3-3 CSF assay plus a clinical duration to death of <2 years

and

- 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

and

- 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.