Creutzfeldt-Jakob Disease (CJD) Case Report Form
for State and Local Health Department Use

Reviewed 01/07/2014

Note to local and/or state health investigator: Complete this form for all persons diagnosed with or suspected of having CJD. If the patient is less than 55 years of age, obtain and review, if available, the patient's hospital admission and discharge summaries, EEG and MRI reports, neurology and psychiatric consultation notes, brain biopsy reports, and autopsy reports and send copies DPHHS Communicable Disease and Epidemiology Section, 1400 Broadway Room C-216, Helena, MT 59620 of fax to 1-800-616-7460. If you abstract information from these hospital records onto the "Form for Investigating Creutzfeldt-Jakob disease in Cases Aged <55 Years," send a copy of it to CDEpi along with a copy of the records. If the patient is suspected of having variant CJD (vCJD) or human chronic wasting disease (CWD), the state health department should notify the Prion Disease Office at CDC (404-639-3091 or 404-639-1170) to discuss next steps.

Reported By

Name: _____

Organization: _____

Phone No. (_____) _____

Date form completed: _ _/_ _/_ _ _ _ (mm/dd/yyyy)

Contact Information

1. Current physician's name: _____

2. Phone number: _____

3. Mailing address: _____

4. Name of family contact: _____ 5. Phone number: _____

6. Has a state or local public health investigator been in touch with this family contact of the case-patient?

1☐ Yes 2☐ No 9☐ Unknown

7. Has family indicated that the health department may contact them again?

1☐ Yes, may contact 4☐ Unknown

2☐ No, may not contact 5☐ Other (specify 8. _____)

3☐ No indication has been made by family

Patient Information/Demographics

9. Patient's code number: __ __ __ __ __ __ __ __ __ __

10. Sex: 1☐ Male 2☐ Female 9☐ Unknown

11. Age at diagnosis: __ __ __ years (**Note:** If the patient is less than 55 years of age, see special instructions in box at the top of this form)

12. Date of birth: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy)

13. Race: 1☐ White
2☐ Black or African American
3☐ Asian
4☐ Native Hawaiian or Other Pacific Islander
5☐ American Indian/Alaska Native
6☐ Other (specify: 14._____)
9☐ Unknown

15. Ethnicity: 1☐ Hispanic/Latino 2☐ Not Hispanic/Latino 9☐ Unknown

16. Patient's state and county of residence at time of diagnosis: _____

17. State in which patient is receiving care: _____

18. Where is the patient currently located? (e.g. name of medical facility, family member living with, etc)

_____

19. As of: _ _/ _ _/ _ _ _ _ (mm/dd/yyyy)

20. If patient has died, specify date of death: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy). If patient has not died skip to Q.24.

21. State in which death occurred: _____

22. Is CJD listed as a cause of death on the certificate? 1☐ Yes 2☐ No 9☐ Unknown

23. If CJD was not listed as a cause of death, what was the primary cause of death as documented on the death certificate?_____

Clinical Information

24. Date of illness onset: _ _ /_ _ _ _ (mm/yyyy)

25. Date of diagnosis of CJD: _ _ /_ _ _ _ (mm/yyyy)

26. Name (and location) of hospital where CJD diagnosis was made: _____

27. Date of initial report to the health department: _ _ /_ _ _ _ (mm/yyyy)

28. Duration of illness: __ __ months

29. Was the patient seen by a neurologist? 1☐ Yes 2☐ No 9☐ Unknown

30. Who diagnosed the patient with CJD? 1☐ Neurologist 2☐ Primary care physician
3☐ Other (specify: _____)

31. Did the patient have any of the following: (Note: If these specific clinical indicators are not mentioned in the medical records but there is wording that might be interpreted as one of these indicators, you are encouraged to discuss those findings with the neurologist or with CDC prion group staff before making clinical assumptions.)

32. Progressive dementia 1☐ Yes 2☐ No 9☐ Unknown

33. Myoclonus 1☐ Yes 2☐ No 9☐ Unknown

34. Visual deficits 1☐ Yes 2☐ No 9☐ Unknown

35. Cerebellar signs
(e.g., poor coordination/ataxia) 1☐ Yes 2☐ No 9☐ Unknown

36. Pyramidal/extrapyramidal signs 1☐ Yes 2☐ No 9☐ Unknown

37. Akinetic mutism 1☐ Yes 2☐ No 9☐ Unknown

Laboratory Testing

38. Were any EEGs performed? 1☐ Yes 2☐ No 9☐ Unknown

39. If yes, did a radiologist or a neurologist report that an EEG was indicative of a CJD diagnosis?
1☐ Yes 2☐ No 9☐ Unknown

40. Were any MRIs performed? 1☐ Yes 2☐ No 9☐ Unknown

41. If yes, did a radiologist or a neurologist report that an MRI was indicative of a CJD diagnosis?
1☐ Yes 2☐ No 9☐ Unknown

42. Were any CSF specimens sent to the National Prion Disease Pathology Surveillance Center?
1☐ Yes 2☐ No 9☐ Unknown

43. If yes, date of lab report: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy) or ☐ Unknown

Result of testing:

44. Initial 14-3-3 1☐ Positive 2☐ Negative 3☐ Ambiguous 9☐ Unknown

45. Repeat 14-3-3 1☐ Positive 2☐ Negative 3☐ Ambiguous 9☐ Unknown

46. Was a brain biopsy performed? 1☐ Yes 2☐ No 9☐ Unknown

47. If yes, date of lab report: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy) or ☐ Unknown

48. Results of testing: _____ or ☐ Unknown

49. If yes, were biopsy specimens sent to the National Prion Disease Pathology Surveillance Center?
1☐ Yes 2☐ No 9☐ Unknown

50. Was an autopsy performed? 1☐ Yes 2☐ No 9☐ Unknown

51. If yes, were autopsy specimens sent to the National Prion Disease Pathology Surveillance Center?
1☐ Yes 2☐ No 9☐ Unknown

52. Was blood or tissue sent to the National Prion Disease Pathology Surveillance Center for genetic testing?

1☐ Yes 2☐ No 9☐ Unknown

53. If yes, date of lab report: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy) or ☐ Unknown

54. Results of testing: PRNP mutation present? 1☐ Yes 2☐ No 9☐ Unknown

55. Results of testing: Codon 129? 1☐ Methionine/Methionine 2☐ Methionine/Valine
3☐ Valine/Valine 9☐ Unknown

56. Were any other types of testing performed to diagnose CJD in this patient?

1☐ Yes 2☐ No 9☐ Unknown

57. If yes, what kind of test was performed and what were the results of testing?

_____

_____

_____

Relevant Past Clinical History

58. Is there history of a definite or probable case of prion disease in a blood relative?

1☐ Yes 2☐ No 9☐ Unknown

59. If yes, what was relationship to patient? _____

Did the patient undergo any of the surgical procedures listed here before onset of the current illness? (If there was more than one surgery in a given category, so indicate and provide the year of each surgery, if known.)

60. Brain surgery 1☐ Yes 2☐ No 9☐ Unknown

61. Year _ _ _ _ (yyyy)

62. Spinal surgery 1☐ Yes 2☐ No 9☐ Unknown

63. Year _ _ _ _ (yyyy)

64. Eye surgery 1☐ Yes 2☐ No 9☐ Unknown

65. Year _ _ _ _ (yyyy)

Did the patient ever receive:

66. A dura mater allograft? 1☐ Yes 2☐ No 9☐ Unknown 67. Year _ _ _ _ (yyyy)

68. A corneal allograft? 1☐ Yes 2☐ No 9☐ Unknown 69. Year _ _ _ _ (yyyy)

70. Human derived pituitary growth hormone? 1☐ Yes 2☐ No 9☐ Unknown

71. First year of receipt _ _ _ _(yyyy)

72. Last year of receipt _ _ _ _ (yyyy)

Other Information

73. Did the patient ever donate blood? 1☐ Yes 2☐ No 9☐ Unknown
(This information will be used to enroll cases in an investigational lookback study to assess the risk of blood borne transmission of CJD.)

74. If yes, when was the last time the patient donated blood? _ _/_ _/_ _ _ _ (mm/dd/yyyy)

75. In what city and state did the patient last donate blood? _____

76. Did the patient live or travel (including military service) in the United Kingdom between 1980 and 1996?

1☐ Yes 2☐ No 9☐ Unknown 77. If yes, list specific years _____

78. Did the patient live or travel (including military service) in other European countries between 1980 and 1996?

1☐ Yes 2☐ No 9☐ Unknown

79. Specify country:_____

80. List specific years _____

81. Specific country:_____

82. List specific years _____

83. Specific country:_____

84. List specific years _____

85. Did the patient ever hunt deer or elk in CO, WY, or NE (circle relevant states)?

1☐ Yes 2☐ No 9☐ Unknown

86. If yes, provide details (e.g., state and area hunted, year hunted)_____

_____

_____

87. Did the patient ever hunt deer or elk in IL, KS, NM, NY, SD, UT, WI, or WV (circle relevant states)?

1☐ Yes 2☐ No 9☐ Unknown

88. If yes, provide details (e.g., state and area hunted, year hunted): _____

_____

_____

89. Did the patient ever knowingly eat deer or elk meat from CO, WY, or NE (circle relevant states)?

1☐ Yes 2☐ No 9☐ Unknown

90. If yes, was the meat known to have tested positive for CWD? 1☐ Yes 2☐ No 9☐ Unknown

91. If the patient did knowingly eat deer or elk meat, provide details: _____

_____

_____

92. Did the patient ever knowingly eat deer or elk meat from IL, KS, NM, NY, SD, UT, WI, or WV (circle relevant states)?

93. If yes, was the meat known to have tested positive for CWD? 1☐ Yes 2☐ No 9☐ Unknown

94 If the patient did knowingly eat deer or elk meat, provide details: _____

_____

_____

Case Classification

95. Prion Disease Classification

- ☐ Sporadic CJD (indicate whether the diagnosis is a definite, probable, or possible case of CJD)
  - ☐ Definite CJD
  - ☐ Probable CJD
  - ☐ Possible CJD
- ☐ Familial prion disease; specify _____
- ☐ Iatrogenic CJD

Mail or Fax Completed Form To

Montana Department of Public Health and Human Services
Communicable Disease and Epidemiology Section
1400 Broadway Room C216
PO Box 202951
Helena MT 59620-2951
Fax Number: 1-800-616-7460

Additional Notes:

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