1. Checklist for Clinicians

“Suspected CJD” is a notifiable disease in New Zealand, to both:

 NZCJDR [cjd.registry@otago.ac.nz](mailto:cjd.registry@otago.ac.nz)

 Local medical officer of health.

*If there are any public health risk factors (page 2) please phone Dr Nick Cutfield 03 4740999 AND your local medical officer of health. If Dr Cutfield unavailable, contact Dr Andrew Chancellor via Tauranga Hospital.*

 Complete public health questions as soon as possible. Patient history can be completed with family, to be emailed to [cjd.registry@otago.ac.nz](mailto:cjd.registry@otago.ac.nz). Please attach relevant investigation reports, clinic and hospital discharge letters.

 Send CSF to Melbourne for 14-3-3 and RT-QuIC (>1mL unspun)

 Provide information and discuss post-mortem with family http://www.labplus.co.nz/clinical-resources/

If post mortem is planned:

 Consent in advance, see https://www.otago.ac.nz/cjd-registry for links to forms.

 Inform mortuary at an early stage. North Island: Auckland Technical Head Forensic Pathology extension 23056. South Island: Christchurch Hospital on-call Mortuary Technician.

 Offer “DNA extraction and storage” on blood pre-mortem in case genetic testing is requested at a later date. Only a clinical geneticist will arrange full PRNP gene sequencing after further genetic counselling.

*Note: PRNP Codon 129 status is part of strain typing on pathology reports, but does NOT constitute PRNP gene sequencing. Whānau can be referred early to NZ Genetics, but ideally diagnosis is formally confirmed before counselling.*

 Inform whānau of CJD Support NZ: <https://www.cjdsupport.org.nz/>

[contactus@cjdsupport.org.nz](mailto:contactus@cjdsupport.org.nz)

B: Suspected CJD Risk Assessment

Please email this page to [cjd.registry@otago.ac.nz](mailto:cjd.registry@otago.ac.nz) as soon as possible, and inform your medical officer of health

Name

NHI DOB

|  |  |  |
| --- | --- | --- |
| Risk Factor | Yes/No/  Not sure | Details, if available |
| **Hormone recipient history**  (hPG/hGH treatment until 1988) |  |  |
| **Surgical history**  e.g. eye, spinal, nasal or neurosurgery |  |  |
| **Blood donation history** |  |  |
| Donation: |  |  |
| Receipt: |  |  |
| **Organ donation or receipt** |  |  |
| Donation: |  |  |
| Receipt:  e.g. Lyodura grafts or corneal transplants |  |  |
| **Travel history**  UK 1980-1996  Europe 1985-2000 |  |  |
| **Family history**  (CJD or other neurodegenerative illness) |  |  |

\*If a known donor, please contact the New Zealand Blood Service Medical Director

C. Notification Questionnaire

Complete with whānau input and return to [cjd.registry@otago.ac.nz](mailto:cjd.registry@otago.ac.nz)

1. Patient Name: NHI:

Sex: M / F / non-binary

Address:

Date of Birth: \_\_\_/\_\_\_/\_\_\_

Country of Birth If not NZ, year of arrival in NZ:

Ethnicity:

If applicable, age and date of death: \_\_\_/\_\_\_/\_\_\_

Place and documented cause of death:

1. Person/s assisting with questionnaire:

Name:

Address:

Mobile phone: Email:

Relationship to patient:

Date questionnaire completed: \_\_\_/\_\_\_/\_\_\_

Name:

Address:

Mobile phone: Email:

Relationship to patient:

Date questionnaire completed: \_\_\_/\_\_\_/\_\_\_

1. Which tests have been done? Please attach results, if available.

*(please tick and attach results if available)*

* EEG
* MRI
* SPECT or PET
* Lumbar puncture
* Brain biopsy
* Genetic tests

4. What was the first symptom? When did it occur?

5. What was the first cognitive, psychological or psychiatric symptom? When did it occur?

6. What was the first neurological or motor symptom that was noticed? When did it occur?

|  |  |  |
| --- | --- | --- |
| 7. Clinical features checklist | Yes/No/Don’t Know | Date of onset |
| Confusion  Forgetfulness  Memory loss  Disorientation  Loss of concentration |  |  |
| Personality changes  Depression  Withdrawal  Apathy/Lethargy  Aggression  Paranoia  Anxiety/Fear  Hallucinations (please describe) |  |  |
| Speech disturbances  slurring  slow  difficulty pronouncing words |  |  |
| Walking problems/ ataxia  Poor coordination  Stumbling  Falling  Staggering |  |  |
| Uncontrolled movements/myoclonus  Twitching  Jerking  Inability to write legibly  Tremors |  |  |
| Visual disturbances  Darting eye movements  Double vision  Blindness  Blurry vision |  |  |
| Unusual physical sensations  pain  tingling  numbness  heaviness |  |  |
| Sleep disturbances  Nightmares  Insomnia  Hypersomnolence |  |  |
| Change in appetite or weight |  |  |
| Abnormal sweating |  |  |
| Stuffy, runny nose, sneezing |  |  |
| Incontinence |  |  |
| Akinetic mutism  (unable to speak or move, locked in) |  |  |

8. Was the patient recently an inpatient at any hospital?

|  |  |  |
| --- | --- | --- |
| Hospital | Date (Month/Year) | Name of Consultant |
|  |  |  |
|  |  |  |
|  |  |  |

9. Name of doctor first consulted for this illness:

Name:

Telephone:

Address:

Date / reason for visit:

10. Usual GP:

Telephone:

Address:

11. Usual Dentist:

Telephone:

Address:

12. Please list any previous GP’s / Doctors (including Psychiatrists) additional to those above.

13. Prior to the onset of their illness, had the patient been previously diagnosed with any other condition (such as diabetes, epilepsy, cancer, depression)? Please specify.

14. Previous surgical procedures:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Y/N/Unsure | If yes, which? | When? (year) | Hospital |
| Brain |  |  |  |  |
| Spinal Cord |  |  |  |  |
| Other neurosurgery |  |  |  |  |
| Spine |  |  |  |  |
| Eyes |  |  |  |  |
| Craniofacial (head, skull, neck, jaws) |  |  |  |  |
| ENT (ear, nose, throat, tonsils) |  |  |  |  |
| Dental (root canal tooth extraction) |  |  |  |  |
| Heart |  |  |  |  |
| Abdominal |  |  |  |  |
| Endoscopy |  |  |  |  |
| Orthopaedic |  |  |  |  |
| Cosmetic |  |  |  |  |
| Other (please specify) |  |  |  |  |

15. Did the patient ever have a lumbar puncture (other than for the diagnosis of their final illness) or any procedure in which a needle was inserted into the spine? Yes / No

*If yes, please provide details*

16. Was the patient ever in hospital prior to this illness for non-surgical reasons? Yes / No

*If yes, please provide details including date and hospital*

17. Did the patient undergo any other invasive medical procedures not otherwise identified above? Yes / No  *If yes, please provide details*

18. Any prior head injury with loss of consciousness or skull fracture? Yes / No

*If yes, please provide details:*

19. Did the patient attend a neurologist (before this illness) Yes / No

*If yes: Doctor/ Reason/Date*

20. Were they in contact with anyone who had a serious dementing illness? Yes / No

*If yes, please provide details:*

21. What medications was the patient exposed to (including eyedrops)?

*If yes, please provide details or attach list from clinic letter or discharge summary*

22. Patient’s marital / partnership status:

23. Prior long-term marriages or partnerships? Yes / No

24. Immediate whānau details:

|  |  |  |  |
| --- | --- | --- | --- |
|  | Mother | Father | Spouse |
| Country of Birth |  |  |  |
| Is relative alive now? |  |  |  |
| If no, age at death |  |  |  |
| Cause of death |  |  |  |
| Place of death |  |  |  |
| Prior to death, was relative confused or unconscious? |  |  |  |
| Did relative suffer from any other illness or disease? |  |  |  |
| Occupation |  |  |  |

25. Patient’s siblings:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Name | Age (now or at death) | Sex | Full or half sibling | Alive / Dead | Cause of death |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |

26. Patient’s children:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Name | Age (now or at death) | Sex | Alive / Dead | Cause of death |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |

27. Is there any family history of neurological conditions, including prion disease or a brain disease associated with mental deterioration? (please tick appropriate answer)

* Prion disease (CJD, GSS, FFI, SFI) *(Please forward results if available)*
* Multiple Sclerosis (MS)
* Alzheimer’s Disease (AD)
* Parkinson’s Disease (PD)
* Hashimoto’s or autoimmune disease
* Lewy Body Dementia (LBD)
* Pick’s disease
* Stroke
* Brain tumor
* Bipolar disorder
* Depression

|  |  |  |  |
| --- | --- | --- | --- |
| Relationship |  |  |  |
| Condition |  |  |  |
| Age at diagnosis |  |  |  |
| Age at death |  |  |  |
| Year of death |  |  |  |
| Duration of illness |  |  |  |
| Autopsy result |  |  |  |
| PRNP test result |  |  |  |
| Mutation detected |  |  |  |
| Codon 129 genotype |  |  |  |

28. Residential history:

|  |  |  |
| --- | --- | --- |
| Address (Town, State) | Years lived there | Local characteristics (proximity to farms, hospitals, factories, etc) |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

29. Occupational history:

|  |  |  |  |
| --- | --- | --- | --- |
| Occupation | Employer | Location | Years |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |

30. Educational history:

|  |  |  |
| --- | --- | --- |
| Institution | Town (State, Country) | Years and Duration |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

31. Eating habits: Normal or Special Diet (please specify):

32. Did they live or work on a farm, or come into close / direct contact with farm produce?

*If yes, please provide details* Yes / No

33. Overseas travel, especially UK 1980 – 1996 and Europe 1985 – 2000

*Destination / Date of travel / Duration of travel*

34. Any additional comments