

CJD surveillance reporting form

I. Information on the person reporting			
Name of person reporting			
Date of reporting	_ _ (dd)	_ _ (mm)	_ _ _ (yyyy)
Name of institution			
Address			
Telephone			
Fax number			
Email address			
II. Patient detail			
Serial number (filled by MOPH)	(Country-Province-Year-##) _ _ _ - _ _ - _ _ _ _ - _ _		
Date of birth	_ _ (dd)	_ _ (mm)	_ _ _ (yyyy)
Sex			
Country of birth			
Town of residence			
District of residence			
Occupation			
Date of onset	_ _ (dd)	_ _ (mm)	_ _ _ (yyyy)
Date of hospital admission	_ _ (dd)	_ _ (mm)	_ _ _ (yyyy)
Age of onset			
Current status	<input type="checkbox"/> Alive	<input type="checkbox"/> Dead	<input type="checkbox"/> Unknown
Date of death	_ _ (dd)	_ _ (mm)	_ _ _ (yyyy)
III. Classification of CJD case			
CJD Subtype	<input type="checkbox"/> Sporadic	<input type="checkbox"/> Familial	<input type="checkbox"/> Unknown
	<input type="checkbox"/> Iatrogenic	<input type="checkbox"/> New Variant	
Level of diagnostic confirmation	<input type="checkbox"/> Definite	<input type="checkbox"/> Possible	<input type="checkbox"/> Not known
	<input type="checkbox"/> Probable	<input type="checkbox"/> Suspect	
IV. If Iatrogenic			
If Iatrogenic	<input type="checkbox"/> Growth hormone	<input type="checkbox"/> Gonadotropin	<input type="checkbox"/> Corneal transplant
	<input type="checkbox"/> Neurosurgery	<input type="checkbox"/> Dura mater graft	<input type="checkbox"/> Other
If other Iatrogenic, specify			
V. If Familial			
Has blood been taken for genetic analysis?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not known
	If yes, Mutation found: _____ Or		
Is there a 1 st degree relative with definite or probable CJD or GSS or FFI?	<input type="checkbox"/> Result awaited	<input type="checkbox"/> Unknown	<input type="checkbox"/> No mutation found
	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not known
	<input type="checkbox"/> CJD	<input type="checkbox"/> GSS	<input type="checkbox"/> FFI

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VI. Clinical Features				
Rapidly progressive dementia	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Cerebella signs	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Myoclonus	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Chorea	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Visual disturbance	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Pyramidal signs	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Extrapyramidal signs	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Rigidity	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Primitive reflexes	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Gait disturbance	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Dysarthria	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Dysphasia	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Dysphagia	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Akinetic mutism	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Seizures	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Paraesthesia/dysaesthesia	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Visual/auditory hallucinations	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Depression	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Delusions	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
Others, specify				
VII. Diagnostic investigations				
EEG	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
If yes, typical CJD tracing	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Lumbar puncture	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Elevated CSF protein</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Elevated CSF white cells</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Positive CSF 14-3-3 protein</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Neuroimaging	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Atrophy on CT</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Basal ganglia or thalamic abnormalities on MRI</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
PrP gene analysis	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Mutation found</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>Codon 129 genotype known</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
<i>If yes, specify:</i>	<input type="checkbox"/> MM	<input type="checkbox"/> MV	<input type="checkbox"/> VV	

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VIII. Neuropathology				
Was a necropsy performed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No		<input type="checkbox"/> Unknown
Histology considered typical (spongiform change, neuronal loss, and astrocytosis)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Other neuropathological features	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Immunocytochemistry	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Western Blott	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Presence of scrapie associated fibrills	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Was samples referred to a specialist center?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Where?				
Comments				
Was a brain biopsy performed during life?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Histology considered typical (spongiform change, neuronal loss, and astrocytosis)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Other neuropathological features	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Immunocytochemistry	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Western Blott	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Presence of scrapie associated fibrills	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Was samples referred to specialist center?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
Where?				
Comments				
IX. Blood donation				
Is the patient a blood donor?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not done	<input type="checkbox"/> Unknown
If yes, date and place of last donation				
X. Other comments				