



## MEETING REPORT

# Annual EuroCJD network meeting 2013

Oslo, 6–7 June 2013

## Background and scope

The European Creutzfeldt–Jakob Disease surveillance (EuroCJD) network was established in 1993 by seven countries to conduct epidemiological surveillance for Creutzfeldt–Jakob disease (CJD) and subsequently enlarged to include more countries and a research component, funded by the European Commission’s Directorate-General for Research and Innovation and Directorate-General for Health and Consumers. The surveillance of variant CJD was regulated in the EU in 2000<sup>i</sup>. The network was evaluated and coordination of the activities was transferred to the responsibility of ECDC in 2007. The activities, including surveillance, were outsourced until 2012, when the reporting of vCJD, including all historical cases was established in The European Surveillance System (TESSy). There are now 25 collaborating centres from EU Member States and EEA countries, and also eight additional countries worldwide, who provide data from national registries to TESSy. The network activities have been coordinated by the UK’s National CJD Surveillance Unit based in Edinburgh and funded by the European Centre for Disease Prevention and Control (ECDC) and national authorities.

The EuroCJD meetings are held annually/biannually and constitute a valuable platform for: 1) the assessment of the latest scientific and diagnostic findings and developments in the field of CJD; 2) the assessment of their impact on the needs of future surveillance; and 3) sharing country-specific experience, case studies and public health activities. The EuroCJD meeting is coupled with a EuroCJD network Steering Group, where group members discuss important epidemiological and scientific findings and their impact on the scope and structure of the existing surveillance system.

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<sup>i</sup> 2000/96/EC: Commission Decision of 22 December 1999 on the communicable diseases to be progressively covered by the Community network under Decision No 2119/98/EC of the European Parliament and of the Council. Official Journal of the European Union. OJ L 028, 03/02/2000 p. 50–53.

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## Summary of the meeting

The EuroCJD network meeting was composed of a Steering Group session on 6 June 2013, attended by the coordinating group members, followed by the EuroCJD network meeting on the afternoon of 6 June and all day on 7 June 2013 in Oslo. The latter was attended by 38 EU/EEA representatives from 24 EU countries and Norway; and 15 participants from eight non-EU countries. The non-EU participants came from all over the world: Argentina, Canada, China, Japan, Mexico, Switzerland, Taiwan and the USA. This indicates the wide interest of some of the world's leading CJD experts in this scientific/public health oriented forum, which is so far unique in the world. The meeting was organised by the UK's National CJD Surveillance Unit based at the University of Edinburgh and funded by ECDC and national authorities. The meeting was chaired by Prof. Robert G. Will and coordinated by Ms Terri Lindsay.

This was the first meeting of the EuroCJD network after the reporting of vCJD cases was transferred to ECDC in 2012. Most Member States have reported their current and historical data on vCJD cases to TESSy.

ECDC is in the process of revising the current network's structure. Hence a EuroCJD network structure proposal collating the inputs of the Steering Group was presented and agreed by the network members. The proposal takes into account the need for continuous monitoring of vCJD cases in Europe (and globally) in this post-peak phase of the epidemic, as a long epidemic tail is forecast. To assess the success of the control measures put in place and to ensure the specificity of the surveillance, the need to include monitoring for other forms of human transmissible spongiform encephalopathy (TSE) was emphasised. This has been the constant view of experts in the field.

Invited speakers from Portugal, Japan, Taiwan, Canada and Mexico presented cases occurring in their respective countries, thus stressing the importance of a global monitoring approach for vCJD as well as the added value of the EuroCJD network meeting as the only existing platform of this kind.

Research findings on new and existing diagnostic tools for CJD were presented. These findings may have a bearing on the existing diagnostic criteria for CJD, resulting in the definition of a new diagnostic algorithm including the novel real-time quaking-induced conversion (RT QuIC) test. The results of the 'prion observations in multi-observer MRI internet study in Europe' (PROMISE), aimed at evaluating the validity of the MRI scan interpretation technique in CJD diagnosis, were also presented. Although the data indicated some shortcomings in the specificity of the diagnostics, the study effectively sensitised radiologists to the challenges of CJD diagnosis.

Other relevant research findings presented included epidemiological studies and case studies on risk factors for vCJD, such as dental procedures, organ and tissue transplant and blood transfusion. Although there is evidence of vCJD transmission through blood transfusion, no other risk factors have been identified to date. In addition, the results of recent studies on the aetiology and pathogenesis of vCJD in animal models (macaques) were presented. These findings have raised the question of the role of prions in some other neurodegenerative diseases like ALS (amyotrophic lateral sclerosis), Parkinson's disease and Alzheimer's disease.

## Conclusions and next steps

The conclusions and way forward from this year's EuroCJD network meeting have been summarised in the three key points below:

- It is crucial to continue the identification and early notification of all new cases of vCJD in the EU/EEA and worldwide, preferably in the frame of all human TSEs, based on the rationale that:
  - the disease has a long incubation period of several years (10–15 median) and stringent control measures in the food chain were implemented at EU level in 1999–2001;
  - the ban on use of ruminant-derived proteins in pigs, poultry and fish feeds has been lifted;
  - there is evidence of secondary transmission via blood transfusion and possibly blood products;
  - continuous monitoring is necessary to identify new and re-emerging clusters/outbreaks (e.g. atypical BSE, new phenotypes, iatrogenic transmission).
- The EuroCJD network will continue to provide the EU with early warning of scientific findings relevant for public health and to ensure preparedness to respond.
- The EuroCJD network is crucial for gathering and disseminating scientific updates/insights on the following topics:
  - new diagnostic techniques and diagnostic algorithms;
  - aetiology of CJD diseases, particularly on the possible association between vCJD/sCJD and with other neurodegenerative diseases.

The meeting was well appreciated and received by all European and international participants. Finally, ECDC would like to thank all the meeting participants, the University of Edinburgh, and the EuroCJD coordination group for their invaluable input to the meeting and to the development of international collaboration in surveillance and control of CJD in the EU.

## Annex 1. Meeting agenda

### Thursday, 6 June 2013

14.00	Introduction and surveillance data update	H Blystad RG Will
14.10	Current status of vCJD <ul style="list-style-type: none"> <li>vCJD in France</li> <li>vCJD in Portugal</li> <li>vCJD in Taiwan</li> <li>vCJD in Canada</li> <li>vCJD in the UK</li> </ul>	JP Brandel S Carpenter L Chin Cheng G Jansen RG Will
15.00	TESSy – overview of reporting	J Takkinen
	Surveillance contact points	
15.30	Coffee	
16.00	Risk factors for vCJD <ul style="list-style-type: none"> <li>Dental treatment</li> <li>Organs and tissues</li> </ul>	A Molesworth
16.20	GWA in vCJD/sCJD	C van Duijn
16.50	Potential new clinical phenotypes	RG Will
17.10	Surveillance needs/objectives	J Takkinen/ RG Will

### Friday, 7 June 2013

09.00	CSF markers of sporadic CJD: the Canadian experience	M Coulthart
09.30	Update on RT QuIC	RSG Knight
10.00	PROMISE Study	RG Will/ A Molesworth
10.30	Coffee	
11.00	CJD surveillance in Japan.	Mizusawa H/ Nakamura Y/ Takumi I/ Yamada M
11.40	Anticipation in CJD	E Mitrova/ M Pocchiari/ A Ladogana
12.10	HgH CJD in Mexico	V Sanchez
12.30	Lunch	
14.00	Reporting of vPSPr	RG Will
14.20	Guidance project/JPND	J de Pedro Cuesta
14.50	Transmissibility of other protein misfolding disorders	RG Will
15.30	Coffee	
16.00	Report on recent activity Future activities for EUROCJD Any other business	RG Will

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16.30	Close	
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## Annex 2. List of participants

Country	Name
Austria	Jasmin Rahimi
Belgium	Amber Lizroth
Bulgaria	Petar Petrov
Cyprus	Savvas Papacostas
Czech Republic	Robert Rusina
Denmark	Susan Cowan
Denmark	Henning Laursen
Estonia	Kuulo Kutsar
France	Jean-Philippe Brandel
France	Lauren Peckeu
Germany	Inga Zerr
Greece	George Agrogiannis
Hungary	Zsuzsanna Molnar
Ireland	Rachel Howley
Italy	Anna Ladogana
Italy	Maurizio Pocchiari
Latvia	Irina Lucenko
Lithuania	Galina Zagrebneviene
Malta	Anthony Gatt
Netherlands	Annemieke Rozemuller
Netherlands	Cornelia van Duijn
Norway	Vahid Bemanian
Norway	Hans Blystad
Poland	Pawel Liberski
Portugal	Stirling Carpenter
Slovakia	Katarína Alberová
Slovakia	Eva Mitrova
Slovenia	Goghly Stokin
Spain	Jesus Pedro Cuesta
Spain	Maria Ruiz
Sweden	Anna-Lena Hammarin
Sweden	Inger Nennesmo
Switzerland	Herbert Budka
UK	Richard Knight
UK	Terri Lindsay
UK	Anna Molesworth

Country	Name
UK	Robert Will
Argentina	Christian Begue
Argentina	Ana Lia Taratuto
Canada	Gerard Jansen
China	Xiaoping Dong
China	Qi Shi
Japan	Hidehiro Mizusawa
Japan	Yosikazu Nakamura
Japan	Ichiro Takumi
Japan	Masahito Yamada
Taiwan	Chin-Cheng Lee
Mexico	Victor Sanchez
USA	Ermias Belay
USA	Pedro Piccardo
USA	Larry Schonberger