National CJD Research and Surveillance Unit

https://www.neurodegenerationresearch.eu/survey/national-cjd-research-and-surveillance-unit/

Principal Investigators

Professor Richard Knight

Institution

University of Edinburgh

Contact information of lead PI
Country

United Kingdom

Title of project or programme

National CJD Research and Surveillance Unit

Source of funding information

NIHR (PRP Ad Hoc Grants)

Total sum awarded (Euro)

€ 8,968,315

Start date of award

01/07/2014

Total duration of award in years

2.7

The project/programme is most relevant to:

Prion disease

Keywords
Research Abstract
Background: CJD has an importance greater than its rarity might suggest; being potentially transmissible from person-to-person and with one form, vCJD, being a zoonotic illness (due to BSE in cattle). Particular concerns include: the magnitude of the primary (diet-related) human vCJD epidemic; the magnitude and significance of subclinical BSE/vCJD infection in the human population; the risk of secondary vCJD transmission through blood, blood products, dentistry, surgery or transplantation; the risks associated with (non vCJD) iatrogenic disease (eg related to human growth hormone or neurosurgery); the possible emergence of new clicico-pathological

phenotypes of prion disease (eg related to BSE infection of non-MM PRNP individuals). There are many uncertainties surrounding these concerns and accurate human population disease data critically underpin decisions about public health protection.
Aims: To continue UK CJD surveillance: identifying cases of CJD and obtaining appropriate clinical, pathological & epidemiological data relevant to the concerns listed above.
Research Plan/Methods: The Unit's methodology is described elsewhere in this document. However, in brief, we investigate suspect cases of CJD, including visits to patients & families throughout the UK and collect relevant clinical & epidemiological data. Pathological confirmation of the diagnosis is undertaken whenever possible. Cases are classified according to established criteria and disease trends analysed in conjunction with our stored historical data. There are a number of separately funded studies that dovetail with this core research-including the TMER study of possible blood transmission of vCJD; the Haemophilia study; the paediatric PIND study and collaborative studies with the Roslin Institute including correlations with their animal transmission studies.
Research Team: The Lead Applicant & Co-Applicant details are given elsewhere. Other Team members include: two sub-consultant grade clinical neurologists, an Operations Director, a Study Data Co-ordinator, a Molecular Geneticist, Neuropathology, protein & CSF laboratory staff, administrative & secretarial support. The Unit has been established since 1990, within the University of Edinburgh.
Impact/Influence: The Unit's identification of vCJD and the first instance of blood transfusion-related vCJD have had obvious impacts on public health policy. Our data have underpinned the considerations of various expert advisory committees (including SEAC, ACDP & SaBTO) and various DH risk assessments. Continuing study will have importance in informing future assessments and policy decisions. Both positive and negative findings (such as further or no further cases of blood-related vCJD) will be important for future policy decisions; negative findings have secure meaning only if good surveillance is in place.

Lay Summary
Further information available at:

Types:
Investments > €500k

Member States:
United Kingdom

Diseases:
Prion disease

Years:
2016

Database Categories:
N/A

Database Tags:
N/A