Communicable diseases – human prion disease and malaria

https://www.neurodegenerationresearch.eu/survey/communicable-diseases-human-prion-disease-and-malaria/

Title of project or programme

Communicable diseases – human prion disease and malaria

Principal Investigators of project/programme grant

Title	Forname	Surname	Institution	Country
Professor	John	Collinge	MRC Clinical Trials Unit	UK

Address of institution of lead PI

Institution	MRC Clinical Trials Unit
Street Address	222 Euston Road
City	London
Postcode	NW1 2DA

Country

- United Kingdom

Source of funding information

Medical Research Council

Total sum awarded (Euro)

805333.12

Start date of award

01-04-2006

Total duration of award in months

48

The project/programme is most relevant to

- Prion disease

Keywords

Research abstract in English

Human prion disease: the aim is to assess new therapies for this rapidly progressive fatal disease, and to identify the most appropriate study designs and outcome measures to make these assessments. Randomised controlled trials are difficult to perform and interpret given the small

number of affected patients who are often incapacitated, necessitating consent from carers with strong views about the appropriateness of interventions. The first UK treatment study in human disease, PRION-1, was therefore designed as a patient preference trial which allowed individuals to choose to receive quinacrine or not, or to be randomised. The trial finished follow-up in March 2007, and found that randomisation was unacceptable to almost all patients/carers. Final results will be published later this year. A second study of pentosan polysulphate was designed as a clinical review of all UK patients who had received this drug which has to be given intraventricularly. It found that it had been given and tolerated at a very wide range of doses (although complications from the surgical procedures were common) and highlighted the lack of standardised management and monitoring. As a consequence, funding has recently been approved to set up a UK cohort of patients with human prion disease who will be monitored using standardised assessments and schedules, regardless of which interventions they choose to receive.

Lay Summary