

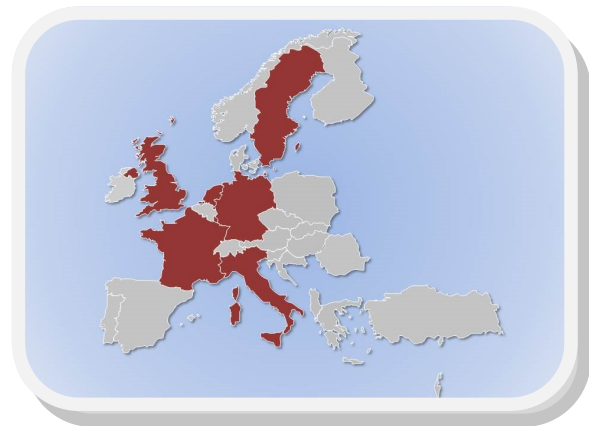
PreNI

Developing a methodological framework for trials in presymptomatic neurodegenerative disease – the Presymptomatic Neurodegeneration Initiative

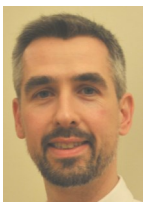
Multicentre presymptomatic cohort studies are underway in a number of different neurodegenerative diseases and will be central to future trials of disease modifying therapies as they provide the opportunity for early intervention. Although each disorder has its own unique issues in relation to such trials, there are shared themes across the different diseases that would benefit from greater discussion and interaction between experts in the field.

This working group will bring together experts in presymptomatic studies of genetic Alzheimer's disease, fronto-temporal dementia, Huntington's disease, Parkinson's disease, prion disease, motor neuron disease and the spino-cerebellar ataxias. The groups will identify the key shared themes including trial design, the use of surrogate endpoints, regulatory perspectives, academic-industry partnerships, recruitment and registers, ethical considerations, and support for participants in trials. Through a series of face-to-face workshops and webex meetings the group will move from sharing individual disease-based perspectives to producing cross-disease guidelines for trials in presymptomatic neurodegenerative disease.


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