

JPND Consortia Meeting
Hilton Hotel, Terminal 4, Heathrow Airport,
London,
06 – 07 October 2014

Monday, October 06, 2014

1.00 pm - 1.30 pm	Meeting Open	Welcome and Introductions Prof. Ammar Al-Chalabi, Prof. Leonard van den Berg, Prof. Orla Hardiman & Dr. Dorothee Lulé (Main Conference Room)
1.30 pm - 2.00 pm		Lunch Break (Main Conference Room)
2.00 pm - 3.00 pm		Session I: Databases Projects: ALL (Main Conference Room) <ul style="list-style-type: none"> • Data collection and infrastructure: ECAS, neuropathology, staging • Data collection and storage: Molecular biomarkers in CSF and peripheral blood • Imaging and Neurophysiologic biomarkers: MRI, MUNE/MUNIX • Treatment Research Institute for the Cure of ALS (TRICALS) • Progeny presentation
3.00 pm - 4.00 pm		Session II: Patient phenotypic stratification Projects: STRENGTH, SOPHIA (Main Conference Room) <ul style="list-style-type: none"> • Definition of the core data sets & data collection - Progeny as central repository • LCCA subgroupings • LCCA validation
4.00 pm - 4.10 pm		Coffee Break
4.10 pm - 4.30 pm		Session III: Iron Horse Presentation (Andreas Jeromin) Projects: ALL (Main Conference Room)
4.30 pm - 5.00 pm		Session IV: Legal matters Projects: ALL (Main Conference Room) <ul style="list-style-type: none"> • SOPs and ethic approvals • Data sharing agreement
6.30 pm		Dinner

Tuesday, October 07, 2014

8:30 am - 9:30 am	Session V: Genetics Projects: STRENGTH, SOPHIA (Main Conference Room) <ul style="list-style-type: none"> Genetic data collection: BioMart European ALS Biobank (EAB) DNA sampling and genotyping Exome/genome sequencing 	
9:30 am - 10:30 am	Session VI: Population registers Projects: ALL (Main Conference Room)	Available for group meetings (Breakout Room)
10:30 am - 11:30 pm	Session VII: Environmental Studies Projects: STRENGTH/SOPHIA (Main Conference Room) <ul style="list-style-type: none"> Environmental/lifestyle data collection Identification of environmental factors affecting age of onset and survival Provision of environmental data Validation of environmental factors 	
11:30 am - 12:00 am	Session VIII: Epigenetics Projects: STRENGTH (Main Conference Room) <ul style="list-style-type: none"> Sample collection MicroRNA profiling DNA methylation analysis Provision of epigenetic factors for interaction modeling 	
12:00 am - 1:00 pm	Session IX: Disease staging and prognostic indicators Projects: SOPHIA, ALS CarE, NEEDS in ALS (Main Conference Room)	
1.00 pm - 2:00 pm	Lunch Break (Aromi Restaurant, Hilton Hotel)	
2:00 pm - 3:00 pm	Session X: Tracking the patient's journey Projects: ALS CarE (Main Conference Room)	Available for group meetings (Breakout Room)
3:00 pm - 3:30 pm	Session XI: Health economics Projects: ALS CarE (Main Conference Room)	Available for group meetings (Breakout Room)
3:30 pm - 4:00 pm	Session XII: Quality of life/ End of life Projects: ALS CarE, NEEDS in ALS (Main Conference Room)	Available for group meetings (Breakout Room)
4:00 pm - 5:00 pm	Session XIII: Project management, dissemination & communication Projects: ALL (Main Conference Room) <ul style="list-style-type: none"> Annual progress reports Communication and dissemination activities Requirements/experience with national funding agencies 	
6:30 pm	Dinner	

**Institute of
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