



## Euro-MOTOR and JPND Consortia Meeting

02 – 05 September 2015

Utrecht

### Wednesday, 02 September, 1800-2200

Euro-MOTOR part I. Data cleaning session

WP2: Clinical Coordination & WP7: Exposome

(Closed meeting: partners Euro-MOTOR WP2 and WP7, Dublin, Milan, Turin, Bari, Utrecht)

19:00 Dinner

### Thursday, 03 September 0945 – 1800

Euro-MOTOR part II

09:45-10:00 Coffee Break

10:00-10:15 Introduction (Project coordinator - Leonard van den Berg)

10:15-10:30 WP1: Project Management (Leonard van den Berg)

10:30-11:00 WP2: Clinical Coordination (Adriano Chio)

11:00-11:30 Coffee Break

11:30-12:00 WP7: Exposome (James Rooney)

12:00-12:30 WP8: Functional Models (Ludo van den Bosch)

12:30-13:00 WP3: Genomics (Jan Veldink)

13:00-14:00 Lunch Break

14:00-14:30 WP4: Proteomics (Daniel Hornburg)

14:30-15:00 WP5: Metabonomics (Hector Keun)

15:30-16:00 WP6: Transcriptomics (Pamela Shaw)

16:00-16:30 Coffee Break

16:30-17:00 WP9: ALS model generation (Lude Franke)

17:00-17:15 WP10: Valorisation (Leonard van den Berg)

17:15-17:45 Meeting conclusions and meeting close (Leonard van den Berg)

19.00 Dinner (Rooftop terrace Leonard van den Berg)





**Friday, 04 September, 0900 – 1700**

**9.00 – 10.30 Session I: Databases**

Projects: ALL

- Data infrastructure: ECAS (Sharon Abrahams), neuropathology (Robin Highley/Pam Shaw)
- Data storage: Molecular biomarkers in CSF and peripheral blood (Markus Otto)
- Imaging and Neurophysiologic biomarkers: MRI (Julian Grosskreutz), MUNIX (Markus Weber)
- Optimization and Harmonization Platform (Leonard van den Berg/Pam Shaw)
- Presentation on Progeny part I – Interface, existing data (Bas Middelkoop)
- Treatment Research Institute for the Cure of ALS (Leonard van den Berg)

**10.30 – 11.00 Session II: Patient phenotypic stratification**

Projects: STRENGTH

- Improved latent class classification system (Ammar Al-Chalabi/Daniel Stahl)
- Use of 5-solution Latent Class Cluster Analysis (Ammar Al-Chalabi/Daniel Stahl)

11.00 – 11.30 Coffee Break

**11.30 – 13.00 Session III: Genetics**

Projects: STRENGTH, SOPHIA

- European ALS Biobank (Leonard van den Berg/Jan Veldink)
- De novo mutations in ALS, TRIO analysis (Leonard van den Berg/Jan Veldink)
- Familial ALS exome sequencing analysis (Leonard van den Berg/Jan Veldink)
- Whole exome/genome sequencing data from existing samples (Leonard van den Berg/Jan Veldink)

13.00 – 14.00 Lunch Break

**14.00 – 14.30 Session IV: Epigenetics**

Projects: STRENGTH, SOPHIA

- Sample collection (Jochen Weishaupt)
- DNA Methylation analysis (Jochen Weishaupt/Janine Kirby)
- MicroRNA profiling (Janine Kirby)

**14.30 – 15.30 Session V: Environmental Studies**

Projects: STRENGTH, SOPHIA

- Environmental/lifestyle data collection (Adriano Chio)
- Identification of environmental factors affecting age of onset and survival (Adriano Chio)





- Provision of environmental data (Adriano Chio)
- Validation of environmental factors (Adriano Chio)

15.30 – 16.00 Coffee Break

16.00 – 17.00 **Session VI: Disease staging and prognostic indicators**

Projects: ALS CarE, NEEDS in ALS, SOPHIA

- Prognostic indicators (Ammar Al-Chalabi)

19.00 Dinner (Utrecht city center)

**Saturday, 05 September, 0900 - 1300**

9.00 – 9:30 Presentation on Progeny part II – Update on design of ALS-CarE section (Bas Middelkoop)

9.30 – 10:00 **Session VII: Tracking the patient's journey**

Projects: ALS CarE

- Tracking the patient's journey (Adriano Chio)

10.00 – 10:30 **Session VIII: Quality of life/ End of life**

Projects: ALS CarE, NEEDS in ALS

- Quality of life/End of life (Johanna Anneser)
- Dorothee Lule's presentation tbc

10.30 – 11.00 Coffee Break

11.00 – 11:30 **Session IX: Health economics**

Projects: ALS CarE

- Health economics (Chris McDermott/Paul Tappenden - still awaiting confirmation)

11:30-12:00 **Session X: Care matrix and optimisation**

Projects: ALS CarE

- Care matrix and optimization (Astrid Janssens)

12.00 – 13:00 **Session XI: Project management, dissemination and project development**

Projects: ALL

- Annual progress reports (speaker tbc)
- Future funding opportunities e.g. H2020 (speaker tbc)

13.00 Closing of the meeting and lunch

