mnda
motor neurone disease
association

24th international
symposium
on ALS/MND

6 – 8 December 2013

Milan
ITALY

Programme

Host: AISLA
(Associazione Italiana Sclerosi Laterale Amiotrofica)

aisla ONLUS
ASSOCIAZIONE ITALIANA
SCLEROSI LATERALE AMIOTROFICA

Organised by the MND Association in co-operation with the
International Alliance of ALS/MND Associations

Organiser of the symposium:

Motor Neurone Disease Association

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Host for the symposium:

AISLA (Associazione Italiana Sclerosi Laterale Amiotrofica)

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Held in co-operation with:

The International Alliance of ALS/MND Associations

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Website: www.alsmndalliance.org

CME Accreditation

Royal College of Physicians (London)

The symposium has been awarded 16 CME credits from RCP (London).

EACCME credits (accepted by AMA) are to be confirmed.

Thank you to the following organisations for supporting the 24th International Symposium

Friday 6 December 2013

Location: Aquarium

SESSION 1 JOINT OPENING SESSION

Chairs: ***W Robberecht*** *(Belgium)* ***V Silani*** *(Italy)*

09.00 – 09.10 Welcome – *W Robberecht (Belgium)*
Opening dignitary – To be confirmed

09.10 – 09.50 ALS in a world of multiple phenotypes – *S Appel (USA)*

09.50 – 10.05 International Alliance Humanitarian Award
International Alliance Forbes Norris Award

10.05 – 10.30 IPG Award and winner's research presentation

10.30 – 11.00 COFFEE
Location: Aquarium / Mizar lobby

Location: Mizar

SESSION 2A NEURONAL VULNERABILITY IN ALS

Chairs: ***C Bendotti*** *(Italy)* ***G Haase*** *(France)*

11.00 – 11.30 Mechanisms underlying selective neuronal vulnerability in ALS - *P Caroni (Switzerland)*

11.30 – 11.45 Size-dependent axon loss in the corticospinal tract in ALS patients with upper motor neuron signs - *F Song (USA)*

11.45 – 12.00 Axon degeneration and axon protection in ALS - *A King (Australia)*

12.00 – 12.15 Inhibitory loss or dysfunction: a primary mechanism in ALS? - *T Dickson (Australia)*

12.15 – 12.30 Peripheral nervous system dysfunction in a rat model and in human motor nerve biopsies of amyotrophic lateral sclerosis - *N Riva (Italy)*

Location: Aquarium

SESSION 2B AUTONOMY AND QUALITY OF LIFE

Chairs: ***O Hardiman*** *(Ireland)* ***Z Simmons*** *(USA)*

11.00 – 11.30 To test or not to test, that is the question - *O Hardiman (Ireland)*

11.30 – 11.45 ALS clinics and the emerging challenge of genetics: a worldwide survey - *S Rudnicki (USA)*

11.45 – 12.00 Developing a model of patient-centered decision-making for amyotrophic lateral sclerosis multidisciplinary care - *A Hogden (Australia)*

12.00 – 12.15 Quality of life, depression and perceived social support in the course of ALS - *D Lulé (Germany)*

12.15 – 12.30 Understanding quality of life in motor neurone disease: qualitative explanations from the Trajectories of Outcome in Neurological Conditions study (TONiC) - *H Ando (UK)*

12.30 – 14.00 LUNCH
Location: Restaurant

Location: Mizar

SESSION 3A RNA PROCESSING AND DYSREGULATION

Chairs: ***S Kwak*** *(Japan)* ***C Lagier-Tourenne*** *(USA)*

14.00 – 14.15 hnRNP A3 binds to GGGGCC repeats of patients with C9orf72 mutations: consequences for RAN translation - *C Haass (Germany)*

14.15 – 14.30 The role of RNA binding protein hnRNP K in ALS and FTD - *D Moujalled (Australia)*

14.30 – 14.45 TDP-43's neurotoxicity is mediated by Fragile X protein and specific mRNA targets - *D Zarnescu (USA)*

14.45 – 15.00 Missense mutations in different domains of the mouse TDP-43 gene cause diverse effects on RNA metabolism - *P Fratta (UK)*

15.00 – 15.15 Systemic dysregulation of TDP-43 binding microRNAs in Amyotrophic Lateral Sclerosis - *J Weishaupt (Germany)*

15.15 – 15.30 Stress granule (SG) dynamics is regulated by autophagic machinery in FUS-related ALS - *U Pandey (USA)*

Location: Aquarium

SESSION 3B COGNITIVE AND PSYCHOLOGICAL CHANGE

Chairs: ***S Woolley*** *(USA)* ***S Abrahams*** *(UK)*

14.00 – 14.15 Screening for cognitive and behaviour change in ALS - *E Niven (UK)*

14.15 – 14.30 High rates of cognitive and behavioural impairment in a large prospective ALS study - *J Murphy (USA)*

14.30 – 14.45 Neuropsychiatric symptoms appear very early in ALS and do not effect survival - *E Mioshi (Australia)*

14.45 – 15.00 Behind the curtain of dysarthria: The nature of language impairment in MND - *P Rewaj (UK)*

15.00 – 15.15 Efficacy of hypnosis-based treatment in ALS and its effect on the caregiver: results of a six-month longitudinal study - *A Palmieri (Italy)*

15.15 – 15.30 Dignity Therapy: A psychotherapeutic intervention to enhance the end of life experience for people with motor neurone disease and their family carers - *B Bentley (Australia)*

15.30 – 16.00 COFFEE
Location: Aquarium / Mizar lobby

Location: Mizar

SESSION 4A IN VITRO MODELLING

Chairs: ***C Shaw** (UK) **S Finkbeiner** (USA)*

16.00 – 16.30 Small molecule screening for neuroprotective agents - *S Finkbeiner (USA)*

16.30 – 16.45 RNA-induced toxicity from the C9orf72 ALS/FTD repeat expansion is mitigated by antisense intervention - *C Donnelly (USA)*

16.45 – 17.00 Comparison of disease mechanisms and therapeutic interventions in primary culture models of multiple familial forms of ALS/MND - *H Durham (Canada)*

17.00 – 17.15 Targeting RNA foci shows a therapeutic effect in iPSC-derived motor neurons from C9orf72 repeat patients - *R Baloh (USA)*

17.15 – 17.30 Therapy development for ALS/MND and frontotemporal dementia with C9orf72 expansion: antisense oligonucleotide mediated reduction in nuclear RNA foci - *C Lagier-Tourenne (USA)*

Location: Aquarium

SESSION 4B QUALITY OF CARE

Chairs: ***J Rosenfeld** (USA) **T Heiman-Patterson** (USA)*

16.00 – 16.35 Advance care planning in ALS – the role of the physician - *G Borasio (Switzerland)*

16.35 – 17.10 The issues of end of life care planning – the final stages - *D Oliver (UK)*

17.10 – 17.30 The AAN ALS Quality Measures: a tool to enhance quality of care - *R Miller (USA)*

POSTER SESSION A *Kindly supported by Cytokinetics*

17.45 – 19.30

Location: Quasar

17.45 – 18.20 Theme 8: Human cell biology and pathology

18.20 – 18.55 Theme 9: In vivo experimental models

18.55 – 19.30 Theme 10: In vitro experimental models

18.55 – 19.30 Theme 12A: Scientific work in progress

Location: Aquarium

17.45 – 18.20 Theme 1: Multidisciplinary care and quality of life

18.20 – 18.55 Theme 2: Respiratory and nutritional management

18.55 – 19.30 Theme 3: Cognitive and psychological assessment and support

Saturday 7 December 2013

Location: Mizar

SESSION 5A THERAPEUTIC STRATEGIES

Chairs: ***P Shaw** (UK) **B Kaspar** (USA)*

08.30 – 09.00 Targeting immune responses in neurodegenerative disease - *S Rivest (Canada)*

09.00 – 09.15 Activation of the brain's choroid plexus for leukocyte trafficking as a therapeutic approach for ALS - *K Baruch (Israel)*

09.15 – 09.30 Recombinant human-derived monoclonal antibodies targeting misfolded SOD1 as novel therapeutics for the treatment of ALS - *J Grimm (Switzerland)*

09.30 – 09.45 Nanobody against SOD1 reduces in vitro aggregation, rescues SOD1-induced axonopathy and extends survival in ALS models - *S Hernandez (Belgium)*

09.45 – 10.00 AAV9-mediated SOD1 downregulation as a future therapy for amyotrophic lateral sclerosis - *B Kaspar (USA)*

Location: Aquarium

SESSION 5B EPIDEMIOLOGY

Chairs: ***A Chiò** (Italy) **E Beghi** (Italy)*

08.30 – 09.00 Endemic ALS: is there anything we can learn from clusters? - *E Beghi (Italy)*

09.00 – 09.15 Feasibility assessment of an epidemiologic study of electroconvulsive therapy and motor neuron disease - *G Mezei (USA)*

09.15 – 09.30 n-3 and n-6 polyunsaturated fatty acid intake and risk of amyotrophic lateral sclerosis: Pooled results from 5 cohort studies - *K Fitzgerald (USA)*

09.30 – 09.45 Interaction between HFE polymorphisms and cumulative lead exposure on the risk of amyotrophic lateral sclerosis - *M Weisskopf (USA)*

09.45 – 10.00 ALS multicenter cohort study of oxidative stress (ALS COSMOS): study methodology, recruitment and baseline demographics and disease characteristics - *H Mitsumoto (USA)*

10.00 – 10.30 COFFEE

Location: Aquarium / Mizar lobby

Location: Mizar

SESSION 6A CELL METABOLISM AND STRESS

Chairs: ***J Atkin*** *(Australia)* ***H Durham*** *(Canada)*

10.30 – 11.00 Mitochondrial etiology of metabolic and degenerative diseases - *D Wallace (USA)*

11.00 – 11.15 Mutated SOD1 causes region specific differences in Ca^{2+}_{cyt} dependent properties of mitochondria from CNS of SOD1 G93A mice and Ca^{2+} dyshomeostasis in fibroblasts of fALS patients - *F N Gellerich (Germany)*

11.15 – 11.30 Mitochondrial metabolic markers in ALS fibroblasts - *H Mitsumoto (USA)*

11.30 – 11.45 Altered growth hormone/insulin balance in hSOD1G93A mice: implications for insulin resistance in amyotrophic lateral sclerosis (ALS) - *S Ngo (Australia)*

11.45 – 12.00 Mechanisms of ER-Golgi transport inhibition in amyotrophic lateral sclerosis - *K Soo (Australia)*

12.00 – 12.15 Mutant TDP-43 leads to pathological accumulation of SMN and its nuclear complexes in motor neurons - *N Perera (Australia)*

12.15 – 12.30 Cyclophilin A interaction network perturbation is a converging patho-mechanism in different forms of amyotrophic lateral sclerosis - *V Bonetto (Italy)*

Location: Aquarium

SESSION 6B NEUROIMAGING

Chairs: ***J Grosskreutz*** *(Germany)* ***M Benatar*** *(USA)*

10.30 – 11.00 Neuroimaging in ALS: Can we see more clearly? - *M Filippi (Italy)*

11.00 – 11.15 The neuroimaging signature of the C9orf72 hexanucleotide repeat in amyotrophic lateral sclerosis: a multimodal MRI study - *P Bede (Ireland)*

11.15 – 11.30 A visual MRI atrophy scale for the ALS-FTD continuum - *E Devenney (Australia)*

11.30 – 11.45 Cerebellar substructure integrity in amyotrophic lateral sclerosis and behavioural variant frontotemporal dementia - *R Tan (Australia)*

11.45 – 12.00 Proton MRSI of cerebellum in ALS - *K Sharma (USA)*

12.00 – 12.15 Discriminant value of ^{18}FDG-PET in amyotrophic lateral sclerosis - *A Chiò (Italy)*

12.15 – 12.30 Development of a PET radioligand for the non-invasive imaging of cannabinoid type 2 receptor - *L Mu (Switzerland)*

12.30 – 14.00 LUNCH

Location: Restaurant

Location: Mizar

SESSION 7A GENETICS AND GENOMICS

Chairs: ***L van den Berg*** *(Netherlands)* ***J Kirby*** *(UK)*

14.00 – 14.15 Reduced C9orf72 gene expression in C9FTD/ALS is caused by trimethylation of histone H3K9 - *V Belzil (USA)*

14.15 – 14.30 Extensive Southern blot study of C9orf72 expansion carriers - *M van Blitterswijk (USA)*

14.30 – 14.45 C9orf72 GGGGCC expanded repeats produce splicing dysregulation which correlates with disease severity in amyotrophic lateral sclerosis (ALS) - *J Cooper-Knock (UK)*

14.45 – 15.00 Motor neuron specific translational profiling in SOD1G93A transgenic mice - *B Zhao (Canada)*

15.00 – 15.15 More evidence supporting perturbation in extracellular and transmembrane domains and of protein signalling by transcriptome analysis of motor neurons from sporadic ALS spinal cords - *J Ravits (USA)*

15.15 – 15.30 Translational study of potential prognostic and diagnostic biomarkers to human samples - *A Calvo (Spain)*

Location: Aquarium

SESSION 7B BIOMARKERS

Chairs: ***B Brooks*** *(USA)* ***N Leigh*** *(UK)*

14.00 – 14.15 Serum creatinine, a biomarker for muscle mass in amyotrophic lateral sclerosis (ALS), predicts loss of ambulation measured by ALS functional rating scale-revised walking item score (ALSFRSw) - *M Fischer (USA)*

14.15 – 14.30 Misfolded SOD1 in blood plasma is an antibody-accessible biomarker for sporadic ALS – *N Cashman (Canada)*

14.30 – 14.45 Proton NMR spectroscopy metabolomics in serum and CSF - *E Gray (UK)*

14.45 – 15.00 Beta-band intermuscular coherence as a biomarker of upper motor neuron dysfunction in motor neuron disease - *S Jaiser (UK)*

15.00 – 15.15 Transglutaminase 6 antibodies in the serum of patients with ALS – is gluten sensitivity involved in motor neuron degeneration? - *V Drory (Israel)*

15.15 – 15.30 Effect of lipid profile on prognosis in patients with amyotrophic lateral sclerosis - *M Rafiq (UK)*

15.30 – 16.00 COFFEE

Location: Aquarium / Mizar lobby

Location: Mizar

SESSION 8A GENETICS

Chairs: *A Al-Chalabi (UK) P Andersen (Sweden)*

16.00 – 16.15 Genetic background effects on lifespan of SOD1 mouse models of ALS - *R Sher (USA)*

16.15 – 16.30 AATXN2 CAG repeat expansions increase the risk for Chinese ALS patients - *X Liu (China)*

16.30 – 16.45 Genome-wide association analyses in Han Chinese identify two new susceptibility loci for amyotrophic lateral sclerosis - *M Deng (China)*

16.45 – 17.00 A genome-wide association meta-analysis identifies a novel locus at 17q11.2 associated with sporadic amyotrophic lateral sclerosis - *I Fogh (UK)*

17.00 – 17.15 Exome sequencing to identify de novo mutations in sporadic ALS trios - *A Gitler (USA)*

17.15 – 17.30 Using public databases of genetic variation to test the pathogenicity of reported ALS mutations - *K Kenna (Ireland)*

Location: Aquarium

SESSION 8B TRIALS AND TRIAL DESIGN

Chairs: *M Cudkowicz (USA) V Meininger (France)*

16.00 – 16.15 The effect of tirasemtiv on functional status in patients with ALS - *J Shefner (USA)*

16.15 – 16.30 Efficacy of Erythropoietin in amyotrophic lateral sclerosis: a multicentre, randomized, double blind, placebo controlled phase III study (EPOS trial) - *G Lauria (Italy)*

16.30 – 16.45 Additional follow-up and biomarker data from a Phase II safety and preliminary efficacy trial of NP001: a novel immune regulator for slowing progression of ALS - *R Miller (USA)*

16.45 – 17.00 Identification of improved clinical outcomes and creatinine-sparing effect of dexpramipexole based on significant inter-study differences in the Phase 2 and Phase 3 (EMPOWER) clinical trials in ALS - *M Bozik (USA)*

17.00 – 17.15 Fetal neural stem cells transplantation in ALS: preliminary results of a phase I clinical trial - *L Mazzini (Italy)*

17.15 – 17.30 Analysis of patients with amyotrophic lateral sclerosis (ALS) treated with autologous differentiated mesenchymal stem cells: a Phase I/II and IIa clinical trial - *D Karussis (Israel)*

POSTER SESSION B *Kindly supported by Cytokinetics*

17.45 – 19.30

Location: Quasar

17.45 – 18.20 Theme 7: Genetics

18.55 – 19.30 Theme 11: Therapeutic strategies

18.55 – 19.30 Theme 12C: Clinical work in progress and care practice

18.55 – 19.30 Theme 12B: Resources and repositories

Location: Aquarium

17.45 – 18.20 Theme 5: Improving diagnosis, prognosis and disease progression

18.20 – 18.55 Theme 4: Imaging, electrophysiology and markers of disease progression

18.20 – 18.55 Theme 3: Epidemiology

Sunday 8 December 2013

Location: Mizar

SESSION 9A GLIAL BIOLOGY AND PATHOLOGY

Chairs: *L Van Den Bosch (Belgium) J Rothstein (USA)*

08.30 – 09.00 Oligodendrocytes: from biology to disease - *P Casaccia (USA)*

09.00 – 09.15 Oligodendrocytes from the ALS mouse model and ALS patients are toxic to motor neurons in vitro - *L Ferraiuolo (USA)*

09.15 – 09.30 Altered astrocytic expression of TDP-43 does not influence motor neuron survival - *A Haidet-Phillips (USA)*

09.30 – 09.45 Mutant TDP-43 triggers astrocytic activation and impaired glutamate transport in primary cultures derived from TDP-43 (A315T) mice - *C Lau (Australia)*

09.45 – 10.00 Human sporadic ALS and rodent familial ALS primary astrocytes are selectively toxic to spinal motor neurons through the same death pathway - *V Le Verche (USA)*

Location: Aquarium

SESSION 9B DISEASE PROGRESSION

Chairs: *A Ludolph (Germany) M de Carvalho (Portugal)*

08.30 – 09.00 ALS/MND as a disease spectrum: time to leave the lumpers behind? - *M Strong (Canada)*

09.00 – 09.15 Being PRO-ACTive – what a clinical trials database can reveal about ALS - *M Leitner (USA)*

09.15 – 09.30 Isometric muscle testing using hand held dynamometry (HHD) in a multicenter ALS trial - *J Shefner (USA)*

09.30 – 09.45 Bulbar ALS: predicting survival from physiological measures of speech - *Y Yunusova (Canada)*

09.45 – 10.00 The soleus H-Reflex delineates upper motor neurone pathophysiology in amyotrophic lateral sclerosis - *N Simon (Australia)*

10.00 – 10.30 COFFEE

Location: Aquarium / Mizar lobby

Location: Mizar

SESSION 10A PROTEIN PROCESSING AND DEGRADATION

Chairs: ***V Bonetto*** *(Italy)* ***A Gitler*** *(USA)*

10.30 – 11.00 Mechanisms of prion-induced toxicity - *A Aguzzi (Switzerland)*

11.00 – 11.15 In vivo propagation of human wild-type SOD1 misfolding in a transgenic mouse model - *N Cashman (Canada)*

11.15 – 11.30 Overexpression of human wild-type SOD1 hastens disease onset and induces earlier presence of mutant SOD1 aggregates in a mouse model of ALS - *E Tokuda (Sweden)*

11.30 – 11.45 Protein stability and neurodegenerative disease - *G Wright (UK)*

11.45 – 12.00 Studying aggregation and distribution of TDP-43 in mammalian cells using biarsenical labelling - *J Ng (UK)*

12.00 – 12.15 Stages of pTDP-43 pathology in ALS - *J Brettschneider (Germany)*

12.15 – 12.30 C9orf72 regulates protein degradation pathways - *M Farg (Australia)*

Location: Aquarium

SESSION 10B RESPIRATORY AND NUTRITIONAL MANAGEMENT

Chairs: ***G Mora*** *(Italy)* ***R Tandan*** *(USA)*

10.30 – 11.00 Assessment and maintenance of caloric needs in ALS - *R Tandan (USA)*

11.00 – 11.15 A multi-centre evaluation of secretion management in patients with motor neurone disease (MND) - *A McGeachen (UK)*

11.15 – 11.30 Oral Secretion Score (OSS) predicts best care interventions and outcomes of patients with ALS/MND using non-invasive ventilation (NIV) - *P Cazzolli (USA)*

11.30 – 11.45 Nocturnal transcutaneous capnography in ALS is a reliable and non-invasive parameter for deciding non-invasive ventilation in ALS patients - *N Pageot (France)*

11.45 – 12.00 Can NIV parameters settings and changes over time predict functional and survival outcome in ALS patients? - *A Pinto (Portugal)*

12.00 – 12.15 Diaphragm functional analysis at the upper and lower spectrum of forced vital capacity (FVC) in ALS/MND: FVC inadequately assesses diaphragm function or upper motor neuron involvement for stimulatability - *R Onders (USA)*

12.15 – 12.30 An ambulatory model of non-invasive ventilation implementation improves survival in motor neurone disease - *N Sheers (Australia)*

12.30 – 14.00 LUNCH

Location: Restaurant

Location: Mizar

SESSION 11 JOINT CLOSING SESSION

Chairs: ***W Robberecht*** *(Belgium)* ***K Talbot*** *(UK)*

14.00 – 14.05 Invitation to Brussels 2014

14.05 – 14.10 Poster Prize presentation

14.10 – 14.20 Late breaking news

14.20 – 15.00 The future of ALS therapeutics - *T Miller (USA)*

Poster sessions

Theme 1 Multidisciplinary Care and Quality of Life

P01 MULTIDISCIPLINARY ALLIED HEALTH PRACTICE GUIDELINES FOR PHYSICAL, SPEECH AND OCCUPATIONAL THERAPY IN ALS
OFFERINGA A, BROEK TEN J, OUDENAARDEN J, SCHAAF VAN DER M

P02 DEVELOPING A REMOTE MULTIDISCIPLINARY CLINIC: INITIAL OBSERVATIONS AND LESSONS LEARNED
KASARSKIS E, VANDERPOOL K, GOULSON D

P03 MULTIDISCIPLINARY TEAMS: EXCELLENT CARE FOR PATIENTS, BUT HOW DO WE CARE FOR OURSELVES?
AXLINE R

P04 PATIENTS' AND PROFESSIONALS' PERSPECTIVES ON CASE MANAGEMENT IN ALS CARE
BAKKER M, CREEMERS H, SCHIPPER K, BEELEN A, NOLLET F, ABMA T

P05 COMPREHENSIVE CARE AND HOME TELEHEALTH FOR VETERANS WITH ALS
KELSEN L, MCCOY S, HOFFMAN P, PATWA H

P06 THE COST OF MANAGING ALS IN A TERTIARY REFERRAL CLINIC: A RETROSPECTIVE CHART REVIEW
CONNOLLY S, TOBIN K, HESLIN C, GALVIN M, HARDIMAN O

P07 THE ROLE ANALYSIS OF THE COORDINATORS FOR PATIENTS WITH INTRACTABLE DISEASES IN JAPAN FROM THE POINT OF VIEW OF CONTINUITY OF CARE
IWAKI M, NAKAI M, TATEISHI T, MURAI H, HAYASHI S, KIRA J

P08 THE TRACE TO THE FIGHT FOR THE IMPROVEMENT IN PALLIATIVE CARE OF THE PATIENTS WITH ALS IN JAPAN
OGINO M, MINAMI S, KANAZAWA N, TAKAHASHI-NARITA K, OGINO Y

P09 PALLIATIVE APPROACH IN AMYOTROPHIC LATERAL SCLEROSIS: A POPULATION-BASED STUDY IN ITALY
ILARDI A, CAMMAROSANO S, MANERA U, BERTUZZO D, PESSIA A, MOGLIA C, CALVO A, VERONESE S, MANAZZA A D, BERSANO G, CHIÒ A

P10 EXAMINING THE RELATIONSHIP OF BULBAR AND LIMB FUNCTION TO PATIENT REPORTED QUALITY OF LIFE: A MULTINATIONAL STUDY
SIMMONS Z, STEPHENS H, FELGOISE S, ABRAHAMS S, CZELL D, GENGE A, GOTKINE M, JACKSON C, KORNGUT L, O'CONNELL C, WEBER M, ZINMAN L

P11 THE EFFECT OF A MULTIDISCIPLINARY CARE PROGRAM ON ALS PATIENTS SURVIVAL
PAIPA A, POVEDANO M, TURON J

P12 EFFECTS OF COGNITIVE BEHAVIOURAL THERAPY (CBT) IN PATIENTS WITH ALS AND THEIR PARTNERS; PRELIMINARY RESULTS
VAN GROENESTIJN AC, SCHRÖDER CD, VISSER-MEILY JM, VAN DEN BERG LH

P13 BREAKING THE NEWS IN AMYOTROPHIC LATERAL SCLEROSIS. ALS PATIENTS' REFLECTIONS ON THE TWO-TIERED APPROACH OF THE ALS CENTRE AMSTERDAM
SEEBER A, POLS A, HIJDRA A, WILLEMS D, DE VISSER M

P14 DIFFICULTIES OF HOME CARE NURSES SUPPORTING INDIVIDUALS WITH AMYOTROPHIC LATERAL SCLEROSIS UNTIL END-OF-LIFE
USHIKUBO M, IIDA M, OKAMOTO K

P15 FRAIL TERMINALITY: HEALTH PROFESSIONALS' AND CARERS' DYNAMIC AND DIVERGING PERCEPTIONS OF CHRONICITY AND TERMINALITY IN ALS/MND
LERUM S, HOLMØY T, SOLBRÆKKE K, FRICH J

P16 PLANNING AHEAD FOR PATIENTS WITH MOTOR NEURONE DISEASE
BATES C, GREENE M, ROSE G, LARRSON E, RADUNOVIC A

P17 THE MEANING OF LOSS FOR PEOPLE WITH AMYOTROPHIC LATERAL SCLEROSIS: IMPACT ON DECISION-MAKING IN CARE
FOLEY G, TIMONEN V HARDIMAN O

P18 WHERE AND HOW DO PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS) DIE?
VARELA CERDEIRA M, SANZ PECES E, GAINZA MIRANDA D, RODRIGUEZ BARRIENTOS R, ALONSO BABARRO A, RODRIGUEZ DE RIVERA F

P19 INTERACTION OF PHYSICAL FUNCTION, QUALITY OF LIFE AND DEPRESSION IN AMYOTROPHIC LATERAL SCLEROSIS: CHARACTERIZATION OF A LARGE PATIENT COHORT
KOERNER S, KOLLEWE K, ABDULLA S, ZAPF A, DENGLER R, PETRI S

P20 BULBAR SYMPTOMS AS PHYSICAL DETERMINANTS OF QUALITY OF LIFE IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS: A SYSTEMATIC REVIEW
MOHAMMAD M, YOUNG C

P21 THE RELATIONSHIP BETWEEN BULBAR FUNCTION AND QUALITY OF LIFE IN PATIENTS WITH ALS
DAVIES J, STEPHENS H, SIMMONS Z

P22 PSYCHOSOCIAL FACTORS AFFECTING QUALITY OF LIFE IN MOTOR NEURONE DISEASE: A SYSTEMATIC REVIEW OF THE LITERATURE
NEE L, GOLDSTEIN L, YOUNG C

P23 FUNCTIONING, FATIGUE AND PSYCHOSOCIAL FEATURES OF MND/ALS: ASSOCIATIONS CHANGE OVER TIME AND IMPACT ON PATIENT QUALITY OF LIFE
GIBBONS C, THORNTON E, EALING J, SHAW P, TALBOT K, TENNANT A, YOUNG C

P24 PHYSICAL THERAPY AND EXERCISES TO PATIENTS WITH ALS
VERSTERRE S, BUUS L

P25 EFFECTS OF ENDURANCE TRAINING ON QUALITY OF LIFE IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS
PRATI C, BASILICO M, SARTORELLI L, PICARDI M, PAIN D, MARINOU K, MORA G

P26 AN EVALUATION OF THE EFFECT OF CORTICOSTEROID INJECTION ON SHOULDER PAIN AND SLEEP QUALITY IN PATIENTS WITH MOTOR NEURON DISEASE
CAMPION A, CALDWELL F, GILSENAN C, MURRAY D, VANCE R, MCGROARTY D, HARDIMAN O

P27 RELATIONSHIP BETWEEN QUALITY OF LIFE AND RESPIRATORY ASPECTS, DIAGNOSIS TIME AND FUNCTIONALITY IN AMYOTROPHIC LATERAL SCLEROSIS
VITAL DE CARVALHO E, SOARES SANTOS N, GONÇALVEZ HOLSAPFEL S, LEICO ODA A, STANICH P, SOUZA BULLE OLIVEIRA A

P28 DISABILITY, ASSISTANCE AND MOBILITY AIDS IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS
ORTIZ-CORREDOR F, MENDOZA-PULIDO C, PEÑA-PRECIADO M, MORA M

P29 UROLOGICAL MANAGEMENT IN AMYOTROPHIC LATERAL SCLEROSIS/MOTOR NEURON DISEASE (ALS/MND): SUBRAPUBIC CATHETERS CAN IMPROVE QUALITY OF LIFE BUT ARE UNDERUTILIZED
ONDERS R, ELMO M, PONSKYL, KAPLAN C, KATIRJI B

P30 HOW MUCH IS THE OPTIMAL INITIAL DOSE OF MORPHINE FOR ALS PATIENTS?
OGINO Y, MIYAKAWA S, URANO Y, KITAMURA E, UCHINO A, KANEKO J, TOMINAGA N, TAKAHASHI-NARITA K, NAGASHIMA K, NAGAI M, OGINO M

P31 VOICE BANKING AND VOICE RECONSTRUCTION FOR MND PATIENTS
VEAUX C, YAMAGISHI J, KING S, COLVILLE S

P32 FINDING IN THE INTELLIGIBILITY SCALE OF SPEECH RELATED TO MYOELASTIC-AERODYNAMIC MECHANISMS OF PATIENTS WITH MOTOR NEURONE DISEASES
ODA AL, SIERRA HNM, ALVES PCL, VECINA ALC, BRUNORO ACV, SILVA R, STANICH P, OLIVEIRA ASB

P33 A SURVEY OF POWER WHEELCHAIR USERS WITH ALS/MND; CHANGING NEEDS OVER TIME
WARD A

P34 EYE-TRACKING COMPUTER SYSTEM UTILIZATION BY PATIENTS WITH ADVANCED AMYOTROPHIC LATERAL SCLEROSIS
SPATARO R, MANNO C, CIRIACONO M, LA BELLA V

P35 SATISFACTION OF ALS CLIENTS AND CAREGIVERS WITH TRAINING ON USE OF AN EYE-GAZE SYSTEM IN A FACILITY SETTING
CHAM E, POIRIER B

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RR02 BENEFITS OF DATA STANDARDIZATION AND HARMONIZATION: A CASE STUDY OF ALSFRS/-R FOR POOLED RESOURCE OPEN-ACCESS CLINICAL TRIALS (PRO-ACT) PLATFORM
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RR03 NEUROBANK™: AN INTERNATIONAL INTEGRATED REPOSITORY OF CLINICAL AND RESEARCH INFORMATION IN ALS/MND
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RR04 GLOBAL UNIQUE PATIENT IDENTIFIER (GUID) SYSTEM IN CONJUNCTURE WITH NEUROBANK™ FACILITATES SCIENTIFIC COLLABORATION WHILE PROTECTING PATIENTS' PRIVACY
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Programme of Events

Friday 6 December

07.00 – 18.00	Registration International Symposium	*Hotel Reception, Ground Floor*
07.00 – 18.00	Speaker Room	*VIP Room, Ground Floor*
07.15 – 08.15	NEALS	*Pegaso, Basement Level 1*
09.00 – 10.30	Symposium Joint Opening Session 1	*Aquarium, Ground Floor*
10.30 / 15.30	Refreshment breaks am/pm	*Aquarium/Mizar Lobby, Ground Floor*
11.00 – 17.30	Symposium Scientific Sessions 2A/3A/4A	*Mizar, Ground Floor*
11.00 – 17.30	Symposium Clinical Sessions 2B/3B/4B	*Aquarium, Ground Floor*
12.30 – 14.00	Lunch	*Andromeda, Ground Floor*
17.45 – 19.30	Poster Session A	*Aquarium/Quasar, Ground Floor /Basement Level 1*

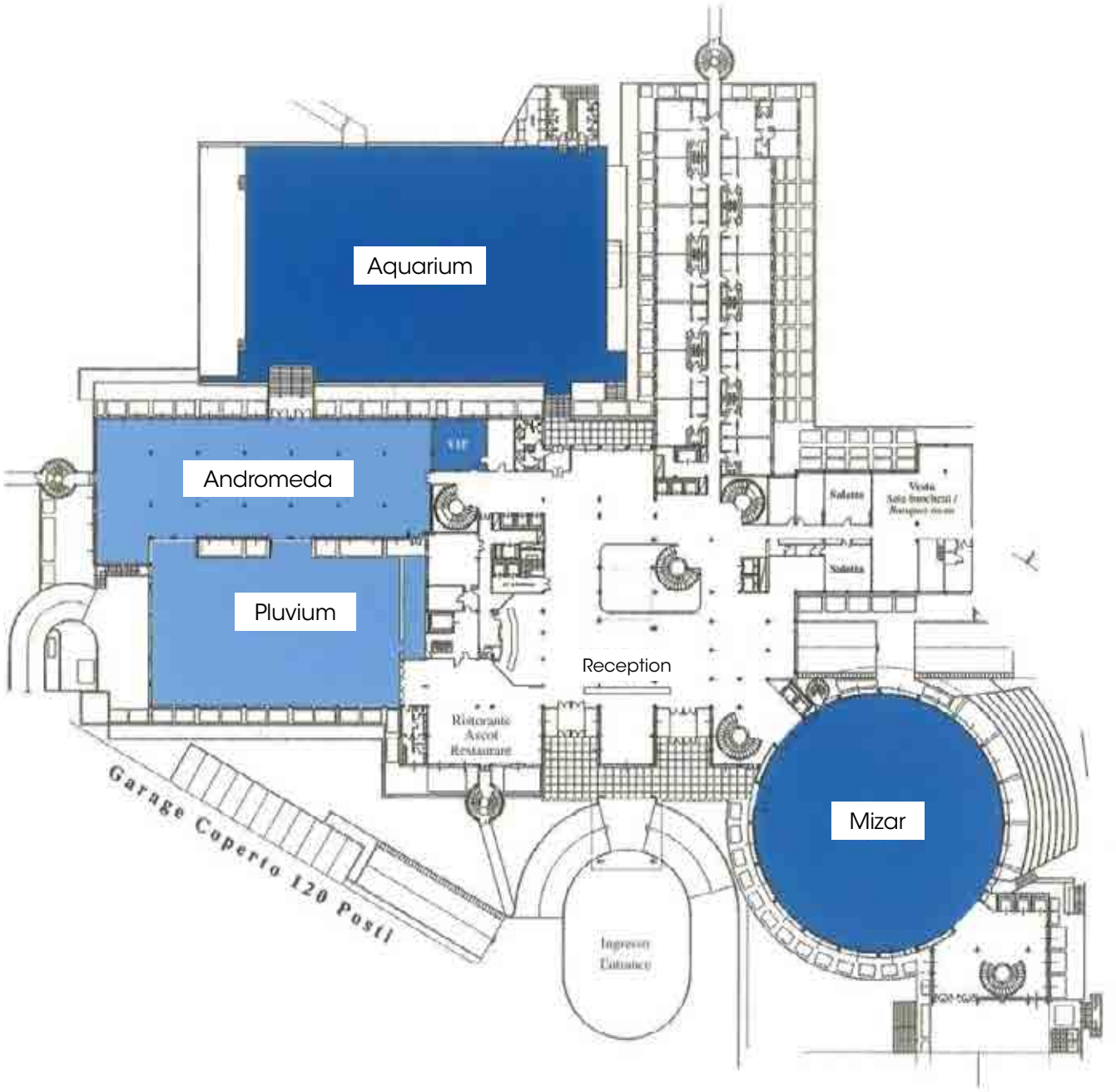
Saturday 7 December

07.00 – 08.00	ALS/RG	*Pegaso, Basement Level 1*
07.00 – 18.00	Speaker Room	*VIP Room, Ground Floor*
07.30 – 18.00	Registration International Symposium	*Hotel Reception, Ground Floor*
08.30 – 17.30	Symposium Scientific Session 5A/6A/7A/8A	*Mizar, Ground Floor*
08.30 – 17.30	Symposium Clinical Session 5B/6B/7B/8B	*Aquarium, Ground Floor*
10.00 / 15.30	Refreshment breaks am/pm	*Aquarium/Mizar Lobby, Ground Floor*
12.30 – 14.00	Lunch	*Andromeda, Ground Floor*
17.30 – 19.00	Cochrane Neuromuscular Group	*Pegaso, Basement Level 1*
17.45 – 19.30	Poster Session B	*Aquarium/Quasar, Ground Floor /Basement Level 1*

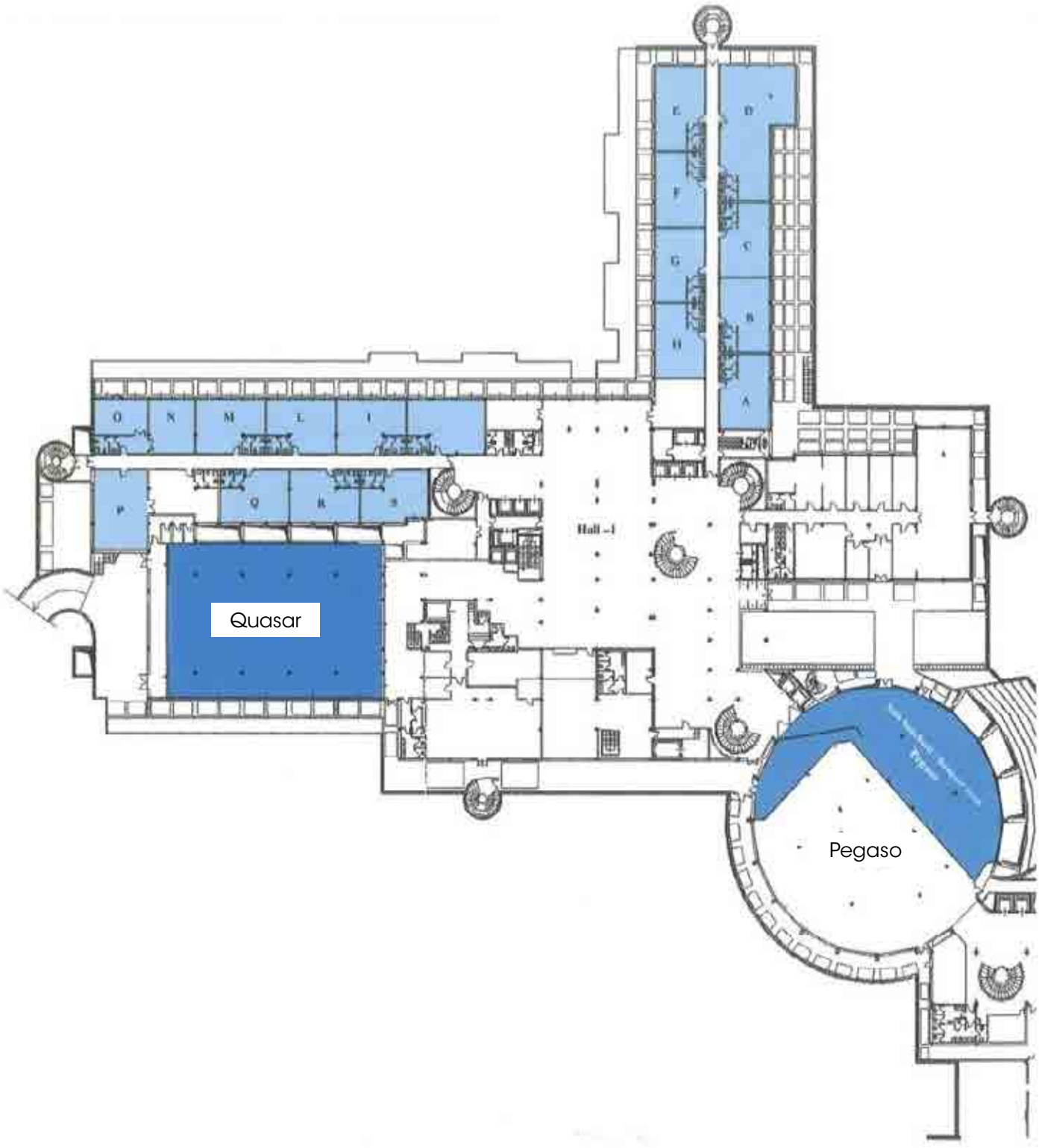
Sunday 8 December

07.00 – 08.30	WALS	*Pegaso, Basement Level 1*
07.00 – 14.00	Speaker Room	*VIP Room, Ground Floor*
07.30 – 1300	Registration International Symposium	*Hotel Reception, Ground Floor*
08.30 – 12.30	Symposium Scientific Sessions 9A/10A	*Mizar, Ground Floor*
08.30 – 12.45	Symposium Clinical Sessions 9B/10B	*Aquarium, Ground Floor*
10.30 – 11.00	Refreshment break	*Aquarium/Mizar Lobby, Ground Floor*
12.30 – 14.00	Lunch	*Andromeda, Ground Floor*
14.00 – 15.00	Symposium Joint Closing Session 11	*Mizar, Ground Floor*

Ground floor



Basement



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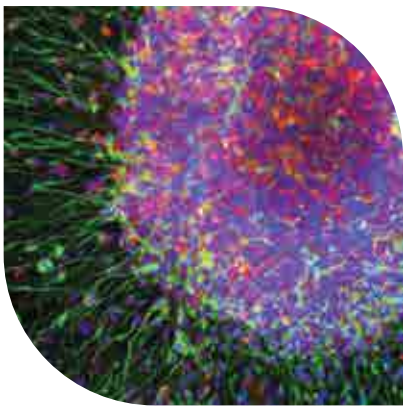

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