

mnda

motor neurone disease
association

24th international
symposium
on ALS/MND

6 – 8 December 2013

Milan
ITALY

Programme and Registration

Host: AISLA

(Associazione Italiana Sclerosi Laterale Amiotrofica)



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

Introduction



24th International Symposium on ALS/MND

6 – 8 December 2013

The International Symposium on ALS/MND is a unique, annual event which brings together leading international researchers and health and social care professionals to present and debate key innovations in their respective fields.

The symposium is planned as two parallel meetings, one on biomedical research and the other on advances in the care and management of people affected by ALS/MND. Joint sessions consider issues of mutual concern, challenging current views and practice.

Organiser of the symposium:



Motor Neurone Disease Association

PO Box 246, Northampton NN1 2PR, UK
Tel: (-) 44 1604 611845 or 611822
Fax: (-) 44 1604 611858
Email: symposium@mndassociation.org
Website: www.mndassociation.org

The 24th International Symposium on ALS/MND is being held in co-operation with:

Host for the symposium:



AISLA (Associazione Italiana Sclerosi Laterale Amiotrofica)

20139 Milano (Lombardia), Viale Ortles 22/4
Tel (-) 39 02 43986673
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The International Alliance of ALS/MND Associations

Email: alliance@als-mnd.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.

Please note: This programme is provisional and subject to final confirmation from all presenters.

Programme changes can be viewed at: www.mndassociation.org/symposium

Contents

Welcome	3
Foreword	3
Satellite meetings	4
Allied professionals' forum programme	5
Symposium programme	6
Travel information	11
Milan – General information	12
Hotel information	13
Conditions of registration	14
Symposium registration form	15
Allied professionals' forum registration form	16

Welcome to Milan!

It is a great honour for AISLA, on its thirtieth anniversary, to be the host for the second time in its history of the International Symposium on ALS/MND and the International ALS/MND Alliance Annual Meeting.

Since 1983, AISLA has consistently and intensively promoted the best support to PALS. Our collaborators and volunteers within our national headquarters and almost 60 regional chapters are all deeply involved in promoting advocacy, education and knowledge about the disease and in meeting the needs of those affected by ALS.

For ten years, AISLA has operated the ALS Listening Centre, where many specialists offer free advice every day on various issues related to ALS. Our chapters all over Italy are working closely with Regional Government to improve assistance to PALS and family, including both financial and social support.

In 2008 AISLA supported the creation of the Nemo Clinical Centre, the first Italian centre specialising in neuromuscular disease. The success of this centre has led to the recent replication of another one in the south of Italy. AISLA also proudly supports research through its partner organization AriSLA – the Italian Agency for Research in ALS – that has supported numerous projects including basic, clinical, translational and technological research. AISLA is a founding member of the International Alliance of ALS/MND Associations.

This unique event gathers the world's greatest minds focusing on ALS and MND to share information and move research ever closer to discovering causes, new treatments and a cure for ALS.

We look forward to personally welcoming you to the Symposium and to the synergy that is created when both scientists and clinicians freely share their strategies, experiences and latest findings in research and treatment, so that one day we can realize our goal of a world free from the effects of ALS.

AISLA, in partnership with the Motor Neurone Disease Association of England, Wales and Northern Ireland, is proud to welcome the international ALS/MND community to the 24th International Symposium on ALS/MND and the 21st International ALS/MND Alliance Meeting. We wish all of you both a memorable and enjoyable stay in our beautiful city of Milan.

Massimo Mauro
President, AISLA Onlus

Foreword

Welcome to the 24th International Symposium on ALS/MND. Recently, a wealth of new data on the genetics and biology of motor neuron degeneration has emerged. New avenues for the understanding of its mechanism have been opened. The speakers and presenters at the symposium will add novel data to these exciting new insights, and invited experts will critically address them. Increasing our knowledge of the biology of this disease will allow us to identify targets for intervention and opens perspectives for novel therapies and therapeutic approaches.

Providing optimal care for ALS/MND patients and their families is the main goal of ALS/MND associations and alliances. Critical evaluation of the treatments and approaches available is necessary to optimally contribute to the improvement of the quality of life of ALS patients and their caregivers. New developments in treatment of ALS patients and novel ideas on how to approach ALS/MND and ALS/MND patients will be presented.

This meeting hopes to contribute to a pathway to cure and care. The contribution from all of you is necessary for this. We are looking forward to a meeting that will bring us closer to our common goal.

Wim Robberecht
Programme Committee Chair

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



CYTOKINETICS



Satellite meetings and events



Date	Meeting	Venue	Time	Contact
2 December	Board of Directors Meeting International Alliance of ALS/MND Associations	Vega	08.00 – 18.00	For further information on all Alliance meetings, please email: alliance@als-mnd.org
3 December	Annual General Meeting and 20th Annual Meeting of the International Alliance of ALS/MND Associations	Quasar	08.00 – 17.00	As above
4 December	20th Annual Meeting of the International Alliance of ALS/MND Associations	Quasar	08.00 – 12.30	As above
4 December	Ask the Experts	Quasar	14.00 – 16.00	As above
4 December	ALS/RG Symposium on Creatinine as Biomarker for Disease Burden in ALS	Pegaso	14.00 – 18.00	For further information on this meeting, please contact: Benjamin Brooks email: Benjamin.Brooks@carolinashealthcare.org
5 December	The use of DNA testing in clinical practise in the care of ALS patients and their relatives	To be confirmed	08.00 – 12.00	Closed meeting
5 December	Allied Professionals' Forum	Mizar	09.00 – 18.00	For further information on all Alliance meetings, please email: alliance@als-mnd.org
5 December	World Federation of Neurology Research Group on ALS/MND	Pegaso	07.30 – 12.30	For further information on this meeting, please contact: Prof Albert Ludolph email: albert.ludolph@rku.de
5 December	European Network for the Cure of ALS (ENCALS)	Pegaso	13.30 – 18.30	For further information on this meeting, please contact: Prof Leonard van den Berg email: L.H.vandenBerg@umcutrecht.nl
6 December	North East ALS Consortium	Pegaso	07.15 – 08.15	For further information on this meeting, please contact: Tara Lincoln email: tlincoln@partners.org
7 December	ALS/RG	Pegaso	07.00 – 08.00	For further information on this meeting, please contact: Dr Jonathan Katz email: KatzJS@cpmcricri.org
7 December	Cochrane Neuromuscular Group	Pegaso	17.30 – 19.00	For further information on this meeting, please contact: Dr Richard Orrell email: r.orrell@ucl.ac.uk
8 December	Western ALS Study Group (WALS)	Pegaso	07.00 – 08.30	For further information on this meeting, please contact: Dr Robert Miller email: MillerRX@cpmcricri.org



Thursday 5 December

Programme

08.30	Welcome and Introductions	Steve and Rod	
08.40	Withdrawal of NIV at the patient's request in MND: Exploration of the issues related to communication	Christina Faull	UK
09.00	Bulbar ALS: A retrospective analysis of patients treated with NIV	Elisa Falcier	Italy
09.20	Optimizing non-invasive ventilation in patients with ALS through serial monitoring of nocturnal oximetry	Deborah Gelinias	USA
09.40	Practical and cost effective solutions for enabling independence in MND patients requiring non-invasive ventilation	Melanie Holmes	Aust
10.00	The 'traffic light' approach to assessing respiratory risk and guiding decision-making for enteral nutrition in ALS	Melanie Lord	UK
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10.20	MORNING TEA		
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10.50	Multidisciplinary teams: How do we care for ourselves while caring for those with ALS?	Rebecca Axline	USA
11.10	Can mindfulness practices improve compassionate care to our PALS and prevent burnout of the health-care provider?	Renee Bricker	USA
11.30	Nurse coaching experience in an ALS clinical centre	Elena Gotti	Italy
11.50	Medical coaching in support of ALS patients and family members	Shiri Ben Arzi	Israel
12.10	Young carers in ALS families	Laurie Fieldman	USA
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12.30	LUNCH AND NETWORKING		
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13.50	Developing best practice guidelines for physical therapy evaluation of individuals with ALS/MND	Sara Feldman	USA
14.10	Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS	Jessica ten Broek-Pastoor	Netherlands
14.50	Recognising the role of occupational therapy in making sense of decision making in Motor Neurone Disease	Malabika Ghosh	UK
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15.10	AFTERNOON TEA		
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15.40	Screening cognitive impairment could improve decision making in ALS?	Stefania Bastianello	Italy
16.00	Pain of isolation	Sarah Lavender	UK
16.20	ComuniCARE PROJECT: AAC apps for people with ALS	Marco Caligari	Italy
16.40	Gadgets and Gizmos II: Continuing to think outside the box	Amber Ward	USA
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17.00	CLOSE		

Co-Chairs: Steve Bell, MND Association; Rodney Harris, MND Victoria

This event has been sponsored by:



and supported by



Registration for the Allied Professionals' Forum is £95

Friday 6 December 2013

SESSION 1

JOINT OPENING SESSION

- | | |
|--|---|
| <p>09.00 – 09.10 Welcome – <i>W Robberecht (Belgium)</i>
Opening dignitary – To be confirmed</p> <p>09.10 – 09.50 ALS in a world of multiple phenotypes –
<i>S Appel (USA)</i></p> | <p>09.50 – 10.05 International Alliance Humanitarian Award
International Alliance Forbes Norris Award</p> <p>10.05 – 10.30 IPG Award and winner's research presentation</p> |
|--|---|

10.30 – 11.00 COFFEE

SESSION 2A

NEURONAL VULNERABILITY IN ALS/MND

- 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)*

SESSION 2B

AUTONOMY AND QUALITY OF LIFE

- 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

SESSION 3A

RNA PROCESSING AND DYSREGULATION

- 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 Moujalied (Australia)*
- 14.30 – 14.45** TDP-43's neurotoxicity is mediated by Fragile X protein and specific mRNA targets - *D Zarnesc (USA)*
- 14.45 – 15.00** Missense mutations in different domains of the mouse TDP43 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)*

SESSION 3B

COGNITIVE AND PSYCHOLOGICAL CHANGE

- 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

SESSION 4A IN VITRO MODELLING

- 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)*

SESSION 4B QUALITY OF CARE

- 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

17.45 – 19.30 Poster Session

Saturday 7 December 2013

SESSION 5A THERAPEUTIC STRATEGIES

- 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)*

SESSION 5B EPIDEMIOLOGY

- 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

SESSION 6A
CELL METABOLISM AND STRESS

- 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 Ca²⁺_{cyt} dependent properties of mitochondria from CNS of SOD1 G93A mice and Ca²⁺ dyshomeostasis in fibroblasts of fALS patients - *F N Gellerich (Germany)*
- 11.15 – 11.30** Mitochondrial metabolic markers in ALS fibroblasts - *K Kirk (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)*

SESSION 6B
NEUROIMAGING

- 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 ¹⁸F-FDG-PET in amyotrophic lateral sclerosis - *A Chio (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

SESSION 7A
GENETICS AND GENOMICS

- 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)*

SESSION 7B
BIOMARKERS

- 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 (ALSFRS_w) - *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? - *B Nefussy (Israel)*
- 15.15 – 15.30** Effect of lipid profile on prognosis in the patients with amyotrophic lateral sclerosis - *M Rafiq (UK)*

15.30 – 16.00 COFFEE

SESSION 8A GENETICS

- 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 - *D Fan (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)*

SESSION 8B TRIALS AND TRIAL DESIGN

- 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 dexamipexole 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

17.45 – 19.30 Poster Session

Sunday 8 December 2013

SESSION 9A GLIAL BIOLOGY AND PATHOLOGY

- 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)*

SESSION 9B DISEASE PROGRESSION

- 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

SESSION 10A

PROTEIN PROCESSING AND DEGRADATION

- 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)*

SESSION 10B

RESPIRATORY AND NUTRITIONAL MANAGEMENT

- 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

SESSION 11

JOINT CLOSING SESSION

- 14.00 – 14.05** Invitation to Brussels 2014
- 14.05 – 14.20** Late breaking news
- 14.20 – 15.00** The future of ALS therapeutics - *T Miller (USA)*

Airports

Milan Malpensa Airport

Malpensa is the principal airport for Milan, serving airlines and flights from all around the world. A fast rail service, the half-hourly Malpensa Express train, connects the airport to Cadorna Stazione Nord in Milan. A ticket costs €9, and the journey takes 50 minutes. There is also a direct shuttle bus service every 20 minutes from Malpensa to Stazione Centrale (Piazza Luigi di Savoia). The journey takes around an hour, and costs around €5. Also stops at the Fiera upon request.

The taxi from Malpensa Airport takes 60 minutes to get to Atahotel Quark.

Website: www.airportmalpensa.com

Milan Linate Airport

Linate is the closest airport to the centre of Milan. The airport is mostly used for domestic and European flights. From Linate an efficient coach service runs directly to Piazza Luigi di Savoia, next to Stazione Centrale. The bus runs every 30 minutes during the day, the journey takes 30 minutes and costs €2. An even cheaper alternative is to take the standard urban ATM bus to Piazza San Babila in the centre (buy your ticket from a machine or newsstand before getting on the bus). This runs every twenty minutes until midnight.

The taxi from Linate Airport takes 20 minutes to get to Atahotel Quark.

Website: <http://linate-airport.com>

Milan Bergamo Airport

Milan Bergamo Airport is at some distance from Milan. However, the airport is used by budget airlines for cheap flights from the UK.

Website: www.bergamoairport.co.uk

Local Transportation

Milan's public transport system is extensive, and you'd be well advised to pick up a map showing routes if you're planning to be in Milan a few days. The network is run by a company called ATM, and tickets are valid on all the types of public transport. A single ticket lasts 75 minutes and costs €1 - you can use it on as many buses and trams as you like, but you are only permitted one metro journey. Most useful for tourists are the 24 hour and 48 hour tickets (€3 and €5.50 respectively). Tickets can be bought at news kiosks, bars and at the Tourist Information Centre in Stazione Centrale. Stamp your ticket in the machine provided the first time you use it (machines are onboard buses and trams, and at the entrance gates to the Metro).

Milan's underground train network, the Metro is quite user-friendly. There are three lines, distinguished by number and colour. M1 (red) is useful for tourist attractions and the Fiera. M3 (yellow) intersects with M1 at Duomo (the station right in front of the Duomo) and with M2 (green) at Stazione Centrale, Milan's main railway station (sometimes marked as Centrale FS). You need to know the final destinations of the train you want, as the platforms are labelled according to the end destination (e.g. Direzione Famagosta). Where a line separates, check the train's destination to be sure you're on the right branch. 'FS' in a name signifies a mainline railway station.

Trams and buses run around the city. Their stops are clearly marked by the side of the street; stops are listed on the sign, with an arrow to show direction of travel. A map comes in handy for working out the location of the stops listed. Take care when getting on or off trams (or driving behind them); they are sometimes constrained to stop for passengers level with the signpost, with enough space for vehicles to pass between the tram and the pavement.

Milan

Milan is one of the most important historical and stylish cities in Italy. One of Europe's four fashion capitals, Milan is also famous for its cuisine, opera, churches, museums and football!

Although it is a working city, as the country's business and financial capital, visitors come in droves for the shopping, eating and nightlife. Milan is known throughout the world for its high fashion and design excellence. Shopping opportunities are at their very best in the Golden Quad area, where streets are filled with leading fashion houses.

The city and its surrounding areas also offer a wide range of museums from major art galleries to museums of science and technology. The Duomo, is the fourth largest Gothic cathedral in Italy and its construction was spread over five centuries. The inspiring cathedral is Italy's last Gothic works and is accentuated by 135 marble spires, 3,400 statues and 96 gargoyles.

Milan is full of wonderful and exciting places to eat out, with a wide choice of every kind of food imaginable. The many stylish locations in Milan offer a wide variety of superb, mouth-watering menus, often with an emphasis on fish and pasta combined with excellent local produce, which make Milan dining an enjoyable experience.

Outside of the city centre, Lake Como, one of the largest and deepest lakes in Italy, is just 40km north of Milan and famous for its villas, picturesque mountains and valleys.

Milan has an efficient transport system which allows you to get around the city quickly and cheaply. Unlimited tourist travel passes allow you to move around without having to worry about buying more than one ticket.

Milan is easily accessible with three airports: Milano Linate (LIN) 7km from the city centre, Milano Malpensa (MXP) 45km from the city centre and Bergamo Orio al Serio (BGY) 50km from the city centre.

Time Zone

Milan is 1 hour ahead of Greenwich Mean Time (GMT).

Electricity

The electrical current in Milan is 220 volts, 50 cycles alternating current (AC), therefore visitors may need an adapter and/or transformer for electrical appliances

Weather

Winters in Milan are cold and rainy. Snow can fall in December and the temperature hovers around zero.

Money Matters

Milan's currency is the Euro (€). You will find cash machines/ATMs in most banks, hotels and shopping centres. Currency exchange is available at banks and kiosks throughout the city and at the airport.

Entry requirements

Visitors to Italy will need to clarify their Visa requirements, visit www.worldtravelguide.net/italy/passport-visa for more details and costs.

Emergency services in Milan

The telephone numbers for emergency services in Milan is 0277271

Italy tourist information site

www.milan.world-guides.com

Official Invitation

An official letter of invitation will be forwarded to any participant on request. However, this invitation implies no obligation, financial or otherwise, by the organizers.

Certificate of Attendance

Certificates of Attendance will be provided for participants.

Milan information:

www.aboutmilan.com

www.milancity.com

www.milan.world-guides.com



Hotel information

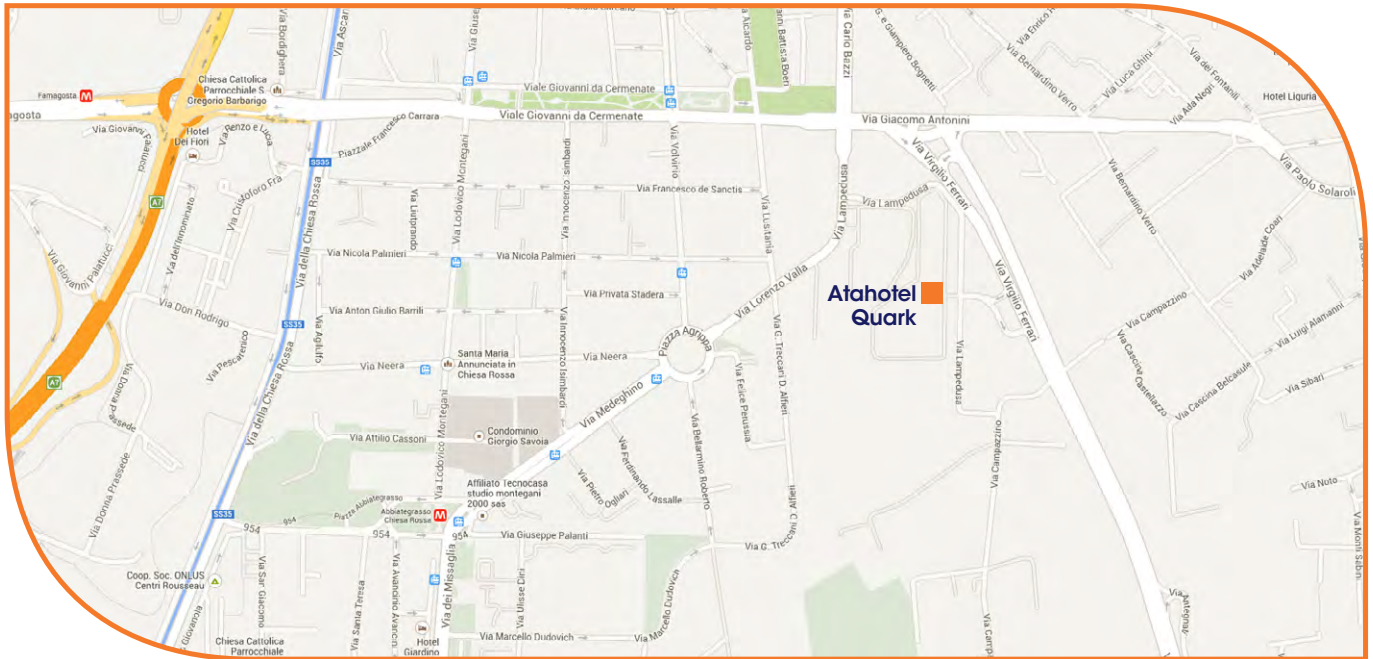
Atahotel Quark
Via Lampedusa, 11/A
20141 Milan
Tel +39 02 84431

Taking advantage of the ALS/MND Symposium special rates:

To book a room on a Bed and Breakfast basis at the hotel at the Symposium rate of €125

Website: www.atahotels.it/en/quark

- Connect to the hotel via www.atahotels.it
- Select Milan as the Destination, then ATAHOTEL Quark Hotel
- Select the Promo Code link and enter MND
- Put in your room requirements



Other Milan Hotels

If you are unable to source rooms at the Atahotel Quark during the symposium period, we have guaranteed rates at other hotels.

Hotel – All 4 Star	Distance from Atahotel Quark				Walk	Mode of transport			Rate* Single B&B inc. VAT, additional city tax of €4 applicable
	Within 15 mins	Within 20 mins	Within 25 mins	Other		Bus	Metro	Other	
MilHotel	●				●				€84 - €119
NH Milanofiori	●						●		€86
NHOW Milan	●						●		€125
Starhotel Anderson	●						●		€145
Madison Best Western		●					●		€115
Doria Grand Hotel							●		€121
Four Points							●		€125
Crowne Plaza Milan		●					●		€125
NH Grand Hotel Verdi		●					●		€125
ATA Executive			●				●		€125
Starhotels Business Palace				3.8 km		●			€119
Hotel La Spezia Milano				2.1 km				●	€103

* To access these rates, please click [here](#) for instructions on how to book a room. Please note that these rates are subject to availability.

General Conditions of Registration

1. It is expressly agreed that the Motor Neurone Disease Association UK, Programme Committee and the Conference Secretariat for 24th International Symposium on ALS/MND, their legal representatives, directors and employees, and their agents, officers and services, shall not be liable for any loss, injury or damage of any kind whatsoever suffered directly or indirectly by the person, possessions or property of any Congress participant or other person during or in connection with the events on the programme or any other activities of 24th International Symposium on ALS/MND for any reason whatsoever no matter howsoever caused.

2. It is agreed that the Organising Committee and the Secretariat for the 24th International Symposium on ALS/MND, and their agents and officers, reserve the right to cancel at any time any or all of the programmed or other activities if this should appear necessary as a result of events which are beyond their control or which they cannot reasonably be expected to influence or for which they are not responsible. Without limiting the generality of the foregoing, such events shall include force majeure, government or other official regulations, natural disasters, strikes or any kind whatsoever, civil, international or other crises, or any other unforeseen occurrence. Decisions regarding the necessity for such cancellation shall be taken by the Motor Neurone Disease Association UK, Programme Committee, or their agents, at their sole discretion and shall be final.

Cancellation Policy

Symposium Registration Fees: Refunds of Conference registration fees paid, less a 25% administration fee, will be granted until 31 October 2013. Details available on request. Cancellation must be received in writing by The Conference Team, MND Association UK before this date.

No refunds will be issued after this date.

Registration form



24th International Symposium on ALS/MND

6 – 8 December 2013

Please print in capitals (one form per delegate)

Title: Last name: First name:

Institution: Job title:

Mailing address: (To send confirmation)

Tel: Fax: Email:

Please indicate any special dietary requirements:

Registration: (Please note registration fees in £ Sterling)

Standard **Late** **Onsite**
29 July–13 Oct **14 Oct–17 Nov** **18 Nov onwards**
Registration £450 £520 £900 £

£ _____

Total enclosed £

Payment Method: Visa Mastercard Bank transfer Cheque/Money order/Bankdraft Amex Switch/Maestro

Credit card number: Issue No:

(shaded boxes are for Switch/Maestro card use only)

Name of cardholder: Valid date: / / Expiry date: / /

For your security, please write the last 3 numbers printed on the reverse of your card.

If Amex the 4 numbers printed on the front of the card

Cardholder's billing address:

Signature: Date: / /

Send Direct Bank Transfer payments to:

MND Association, Lloyds TSB Bank plc, George Row, Northampton NN1 2PR
Account No. 02952679 Sort Code: 30-96-09 BIC: LOYDGB21071 IBAN: GB82 LOYD 3096 0902 9526 79

Please submit this form with your payment made out to:

Motor Neurone Disease Association, PO Box 246, Northampton NN1 2PR United Kingdom

A copy of your bank transfer **must** accompany your Registration Form.
Payments should be made gross of bank charges that may be incurred.

I agree to the use of the data on this form for the following purposes:

Educational opportunities on ALS/MND Reservations, booking and ticket use
Purchase/Supplier administration Disclosure to other ALS/MND organisations

Signed _____

Registration form



International Alliance
of ALS/MND Associations

Allied Professionals' Forum

Thursday 5 December 2013

This form should be completed by healthcare professionals wishing to attend the allied professionals' forum only.

Please print in capitals (one form per delegate)

Title:	Last name:	First name:
Institution:		Job title:
Mailing address: (To send confirmation)		
Tel:	Fax:	Email:

Please indicate any special dietary requirements: _____

Registration: (Please note registration fees in £ Sterling)

<input type="checkbox"/> APF only: until 17 Nov	<input type="checkbox"/> Onsite: 18 Nov onwards
Registration £105	£150

Total enclosed £ _____

Payment Method: Visa Mastercard Bank transfer Cheque/Money order/Bankdraft Amex Switch/Maestro

Credit card number:

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 Issue No:

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