Programme and Registration

Host: The ALS Association (ALSA)

Organised by the MND Association in co-operation with the International Alliance of ALS/MND Associations
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 clinical understanding and management of the disease. 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
e-mail: symposium@mndassociation.org
website: www.mndassociation.org

Host for the Symposium:
The ALS Association
1275 K Street NW Suite 1050
Washington, DC 20005
tel: 800.782.4747
fax: 818.880.9006
e-mail: alsainfo@alsa-national.org
website: www.alsa.org

The 21st International Symposium on ALS/MND is being held in co-operation with:
The International Alliance of ALS/MND Associations
Secretariat: PO Box 246, Northampton
NN1 2PR, UK
tel: (-) 44 1604 611821
fax: (-) 44 1604 624726
e-mail: alliance@alsmndalliance.org

CME
The Symposium has been awarded 18 CME credits from RCP London. CME accreditation is being sought from EACCME (accepted by AMA)

Please note: this programme is provisional and subject to final confirmation from all presenters.
Programme changes can be viewed at www.mndassociation.org

EXHIBITORS
Exhibitors’ stands will be on display from 11 December 2010

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Welcome from The ALS Association

The ALS Association is proud to host the 21st International Symposium on ALS/MND. This year marks an especially exciting year for clinical and scientific research with many new avenues being explored, including the discovery of new genes linked to familial ALS and the key clinical trials being undertaken, both in the United States and Europe.

The ALS Association has been committed to global research and collaborative partnerships with organizations sharing a common goal, and we believe strongly that meetings such as these are critical to moving the research forward. Over the years the international meeting has grown significantly and attracts world leaders in the field of ALS/MND research and clinical management.

During 2010, The ALS Association is commemorating its 25th year in the fight against ALS/MND (or Lou Gehrig’s Disease, as it is also known in the US). In those years, we have seen many advances in ALS/MND research, not the least of which is the discovery of SOD1 mutation’s linkage to the disease. This discovery led to the development of the transgenic SOD1 mouse model and new opportunities for experimentation.

The International Symposium offers the opportunity for the scientists around the globe to meet and exchange ideas to expand the search for clues into the cause and cure of this devastating disease. We invite everyone to freely share their knowledge and strategies so that we can relegate ALS/MND to the history books, once and for all.

The ALS Association is honored to welcome the research community to both the International Symposium and the 18th annual meeting of the International Alliance of ALS/MND Associations 2010, and we hope you enjoy your visit to Orlando.

Jane Gilbert
President and CEO
The ALS Association

The purpose of the International Symposium on ALS/MND is to make progress in our understanding of motor neuron degeneration and to improve care for patients with ALS/MND, with the ultimate goal of finding a treatment for this disease. This year’s meeting will undoubtedly contribute to that purpose. Exciting new findings on ALS genetics and biology, and the results on newly generated models will be presented. Novel issues in the care and treatment of ALS patients will be analyzed and discussed. Distinguished guest speakers will address new developments in both the basic and clinical sciences of motor neuron degeneration.

The number of abstracts submitted for the 2010 meeting has been unprecedentedly high, as was their quality. Therefore, during the 21st meeting, we will devote even more time and attention to the poster sessions to encourage discussion of the data presented on them. We are very grateful to all their authors and to all invited speakers for making the meeting a scientific and clinical highlight.

We hope that the meeting will be one more step to reaching our goal: finding a cure for ALS/MND.

Wim Robberecht
Programme Committee Chair
<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Venue</th>
<th>Time</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 December</td>
<td>Board of Directors Meeting International Alliance of ALS/MND Associations</td>
<td>Milagro</td>
<td>09.00 – 18.00</td>
<td>For further information on all Alliance meetings, please contact: tel: (+) 44 (0) 1604 611821 fax: (+) 44 (0) 1604 624726 email: <a href="mailto:alliance@alsmndalliance.org">alliance@alsmndalliance.org</a></td>
</tr>
<tr>
<td>8 December</td>
<td>Annual General Meeting and 18th Annual Meeting of the International Alliance of ALS/MND Associations</td>
<td>Med 6/7</td>
<td>08.30 – 17.00</td>
<td>As above</td>
</tr>
<tr>
<td>9 December</td>
<td>18th Annual Meeting of the International Alliance of ALS/MND Associations</td>
<td>Med 6/7</td>
<td>09.00 – 12.30</td>
<td>As above</td>
</tr>
<tr>
<td>9 December</td>
<td>Ask the Experts</td>
<td>Med 6/7</td>
<td>14.00 – 18.00</td>
<td>As above</td>
</tr>
<tr>
<td>10 December</td>
<td>Allied Professionals’ Forum</td>
<td>Med 6/7</td>
<td>09.00 – 17.30</td>
<td>As above</td>
</tr>
<tr>
<td>10 December</td>
<td>World Federation of Neurology Research Group on ALS/MND</td>
<td>Med 8</td>
<td>07.30 – 12.30</td>
<td>For further information on this meeting, please contact: Prof Albert Ludolph tel: (+) 49 7311771200 fax: (+) 49 7311771202 email: <a href="mailto:albert.ludolph@rku.de">albert.ludolph@rku.de</a></td>
</tr>
<tr>
<td>10 December</td>
<td>European ALS/MND Consortium</td>
<td>Med 6</td>
<td>13.30 – 18.30</td>
<td>For further information on this meeting, please contact: Leonard van den Berg email: <a href="mailto:lberg@umcutrecht.nl">lberg@umcutrecht.nl</a></td>
</tr>
<tr>
<td>10 December</td>
<td>ALS/MND Nursing Mini-Symposium</td>
<td>Med 6/7</td>
<td>18.00 – 21.00</td>
<td>For further information on this meeting, please contact: Jennifer Armstrong tel: (+) 312 695 0709 email: <a href="mailto:jarmstrong@nmff.org">jarmstrong@nmff.org</a></td>
</tr>
<tr>
<td>11 December</td>
<td>North East ALS Consortium</td>
<td>Med 6</td>
<td>07.15 – 08.15</td>
<td>For further information on this meeting, please contact: Breen Power tel: (+) 617 724 7398 email: <a href="mailto:bpower@partners.org">bpower@partners.org</a></td>
</tr>
<tr>
<td>12 December</td>
<td>Western ALS Study Group (WALS)</td>
<td>Med 6</td>
<td>07.30 – 09.00</td>
<td>For further information on this meeting, please contact: Dr Robert Miller email: <a href="mailto:MillerRX@cpmcrci.org">MillerRX@cpmcrci.org</a></td>
</tr>
<tr>
<td>12 December</td>
<td>Cochrane Neuromuscular Group</td>
<td>Segura 5</td>
<td>17.30 – 19.00</td>
<td>For further information on this meeting, please contact: Dr Robert Miller email: <a href="mailto:MillerRX@cpmcrci.org">MillerRX@cpmcrci.org</a></td>
</tr>
<tr>
<td>13 December</td>
<td>ALS/RG</td>
<td>Med 6</td>
<td>07.30 – 08.30</td>
<td>For further information on this meeting please contact: Francine Murphy email: <a href="mailto:fmurphy@partners.org">fmurphy@partners.org</a></td>
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</tbody>
</table>
# ALLIED PROFESSIONALS’ FORUM - PROGRAMME - Friday 10 December

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>08.30</td>
<td>Welcome and Introduction</td>
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<tr>
<td>08.40</td>
<td>Palliative care in an ALS clinic? Absolutely!</td>
<td>B Segal</td>
<td>USA</td>
</tr>
<tr>
<td>09.00</td>
<td>The impact of equipment on relationships</td>
<td>B Taylor</td>
<td>UK</td>
</tr>
<tr>
<td>09.20</td>
<td>The emerging American style of incorporating palliative care into ALS/MND</td>
<td>K Cross</td>
<td>USA</td>
</tr>
<tr>
<td>09.40</td>
<td>Working in partnership to maintain quality of life in a rural community — mobility and environmental controls</td>
<td>K Thomas</td>
<td>UK</td>
</tr>
<tr>
<td>10.00</td>
<td>Resolving pain, contracture and dizziness: A prescription for good quality of life for people diagnosed with ALS</td>
<td>L Cates</td>
<td>USA</td>
</tr>
<tr>
<td>10.20</td>
<td>Refreshment Break</td>
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<tr>
<td>10.50</td>
<td>Yoga and ALS: It’s all in the breathing</td>
<td>R Rhodes</td>
<td>USA</td>
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<tr>
<td>11.10</td>
<td>Patients with cognitive change — the challenge for families and professionals</td>
<td>D Oliver</td>
<td>UK</td>
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<tr>
<td>11.30</td>
<td>When someone close has MND</td>
<td>S Schillerstrom</td>
<td>UK</td>
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<tr>
<td>11.50</td>
<td>A study comparing three low-tech communication methods for people with only eye movement</td>
<td>A Roman</td>
<td>USA</td>
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<tr>
<td>12.10</td>
<td>Lunch</td>
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<tr>
<td>13.30</td>
<td>Two heads are better than one — a team approach</td>
<td>L Boyle</td>
<td>USA</td>
</tr>
<tr>
<td>13.50</td>
<td>To sleep, perchance to dream. . .</td>
<td>L Guion</td>
<td>USA</td>
</tr>
<tr>
<td>14.10</td>
<td>Should sleep Studies be included in clinical management of ALS? Improving communication between the ALS centre and caregivers in the community.</td>
<td>S Feldman</td>
<td>USA</td>
</tr>
<tr>
<td>14.30</td>
<td>Withdrawal of non-invasive ventilation</td>
<td>D Oliver</td>
<td>UK</td>
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<tr>
<td>14.50</td>
<td>Living better for longer: Facilitating a co-ordinated multidisciplinary approach to MND through ‘one stop shop’ online resources</td>
<td>C Birks</td>
<td>Australia</td>
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<tr>
<td>15.10</td>
<td>Refreshment Break</td>
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<tr>
<td>15.40</td>
<td>The Motor Neurone Disease Year of Care</td>
<td>J Connell</td>
<td>UK</td>
</tr>
<tr>
<td>16.00</td>
<td>The Oxford ALS Nutrition Clinic: Improving the enteral nutrition pathway for patients and carers</td>
<td>M Lord</td>
<td>UK</td>
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<tr>
<td>16.20</td>
<td>Take a break from ALS/MND</td>
<td>R Harris</td>
<td>Australia</td>
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<tr>
<td>16.40</td>
<td>Summary and Close</td>
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Registration for the Allied Professionals’ Forum is $150 both for those attending this day only and for health and social care professionals who have registered for the International Symposium.

*This event has been kindly sponsored by ALS Hope Foundation.*
Saturday 11 December 2010
21st International Symposium on ALS/MND

PROGRAMME

SESSION 1  Joint Opening Session
08.30 – 08.35 Welcome – W Robberecht (Belgium)
08.35 – 08.45 Welcome – M Weinberg, President of the National Health Council (USA)
08.45 – 09.15 New perspective on ALS as TDP-43 proteinopathies – V Lee (USA)
09.15 – 09.45 AAN practice parameters: What they tell us and what they don’t – R Miller (USA)
09.45 – 10.00 Presentation of the Forbes Norris Award by the International Alliance of ALS/MND Associations

10.00 – 10.30 COFFEE

SESSION 2A  RNA Biology in ALS
10.30 – 11.00 Using embryonic stem cells to study motor neuron/glia interactions in ALS – T Maniatis (USA)
11.00 – 11.15 Role of RNA processing in the pathogenesis of ALS – C Lagier-Tourenne (USA)
11.15 – 11.30 Genetic and biochemical analysis of TDP-43 proteinopathy – R Tibbetts (USA)
11.30 – 11.45 Characterizing the role of TDP-43 in ALS – B Freibaum (USA)
11.45 – 12.00 RNA targets of TDP-43 identified using UV-CLIP are deregulated in ALS – J Robertson (Canada)
12.00 – 12.15 Increasing autophagy rescues neurodegeneration in flies lacking Adar RNA editing – S Paro (UK)
12.15 – 12.30 miRNA dysregulation in human sporadic ALS – T Möller (USA)

SESSION 2B  Autonomy and Quality of Life
10.30 – 11.00 Quality of life: individual values, standardized assessment? – R Cohen (Canada)
11.00 – 11.30 The Oregon Death with Dignity Act: Why do patients request physician assisted death? – L Ganzini (USA)
11.30 – 11.45 Do religiosity and spirituality correspond with ALS patients’ views on end of life issues? An explorative study with ALS patients and their primary caregivers – R Stutzki (Switzerland)
11.45 – 12.00 The diagnostic journey from symptom onset; experiences of people with MND and the family carers – M O’Brien (UK)
12.00 – 12.15 Communication strategies that ALS patients use at the end of life: results of a three year survey – A Brownlee (USA) and L Bruening (USA)
12.15 – 12.30 An advance-care planning decision aid for patients with amyotrophic lateral sclerosis – A Brothers (USA)

12.30 – 14.00 LUNCH
### Saturday 11 December 2010

**SESSION 3A Lessons from other Diseases**

<table>
<thead>
<tr>
<th>Time</th>
<th>Title</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>14.00</td>
<td>RNA problems and solutions: lessons from myotonic dystrophy</td>
<td>C Thornton (USA)</td>
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<tr>
<td>14.35</td>
<td>The Role of RNA splicing in spinal muscular atrophy</td>
<td>L Pellizzoni (USA)</td>
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<tr>
<td>15.10</td>
<td>Mutant small heat shock protein 27 (HSPB1) mice recapitulate axonal</td>
<td>C D’Ydewalle (Belgium)</td>
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<td></td>
<td>Charcot-Marie-Tooth disease and distal hereditary motor neuropathy</td>
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<td>phenotypes</td>
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**SESSION 3B Care Education and Practice**

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<tr>
<th>Time</th>
<th>Title</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>14.00</td>
<td>Palliative care in terminal illness: Impact on healthcare professionals</td>
<td>V Jackson (USA)</td>
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<tr>
<td>14.30</td>
<td>Development, implementation and testing of an educational program to</td>
<td>R McConigley (Australia)</td>
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<td>guide palliative care for people with motor neuron disease</td>
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<tr>
<td>14.45</td>
<td>Pain in ALS: frequency and characteristics in a population based</td>
<td>A Calvo (Italy)</td>
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<td>series</td>
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<tr>
<td>15.00</td>
<td>Patient care co-ordination at Carolinas Neuromuscular/ALS – MDA</td>
<td>N Williams (USA)</td>
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<td>Centre: nursing management of e-patients and t-patients</td>
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<tr>
<td>15.15</td>
<td>A national study of amyotrophic lateral sclerosis multidisciplinary</td>
<td>Z Simmons (USA)</td>
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<td></td>
<td>clinic utilization</td>
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### 15.30 – 16.00 COFFEE

**SESSION 4A Emerging Disease Models**

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<tr>
<th>Time</th>
<th>Title</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>16.00</td>
<td>TDP-43 mutant transgenic mice develop biochemical and pathological</td>
<td>J-P Julien (Canada)</td>
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<tr>
<td></td>
<td>features of amyotrophic lateral sclerosis and frontotemporal lobar</td>
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<td>dementia</td>
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<tr>
<td>16.15</td>
<td>A new mouse model of ALS carrying a point mutation in the mouse</td>
<td>P Joyce (UK)</td>
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<td>SOD1 gene</td>
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<tr>
<td>16.30</td>
<td>Development and characterisation of a zebrafish model of mutant</td>
<td>M Da Costa (UK)</td>
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<td></td>
<td>SOD1 mediated motor neuron disease</td>
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<tr>
<td>16.45</td>
<td>Novel zebrafish models to investigate ALS disease pathogenesis</td>
<td>S Sakowski (USA)</td>
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<tr>
<td>17.00</td>
<td>Mutant HFE H63D protein is associated with prolonged ER stress and</td>
<td>Y Liu (USA)</td>
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<tr>
<td></td>
<td>decreased neuronal viability in ALS</td>
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<tr>
<td>17.15</td>
<td>Dysregulation of ER stress signalling by ALS-related P56S VAPB</td>
<td>K Kanekura (USA)</td>
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<tr>
<td></td>
<td>mutant</td>
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**SESSION 4B Surrogate Markers**

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<thead>
<tr>
<th>Time</th>
<th>Title</th>
<th>Presenter</th>
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</thead>
<tbody>
<tr>
<td>16.00</td>
<td>Validation of a new device to measure disease progression in ALS</td>
<td>P Andres (USA)</td>
</tr>
<tr>
<td>16.15</td>
<td>Muscle ultrasonography as a diagnostic tool for ALS: a diagnostic</td>
<td>I Arts (Netherlands)</td>
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<td>study according to the STARD criteria</td>
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<tr>
<td>16.30</td>
<td>A novel CMAP scan-based progression score for motor neuron disease</td>
<td>E Maathuis (Netherlands)</td>
</tr>
<tr>
<td>16.45</td>
<td>Further evidence for multisystem involvement in ALS: multiparametric</td>
<td>D Lulé (Germany)</td>
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<td></td>
<td>MRI of sensory stimulation</td>
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<tr>
<td>17.00</td>
<td>Baseline corticospinal tract MRI reflects change in disability at</td>
<td>I Abraham (UK)</td>
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<tr>
<td></td>
<td>six month follow up</td>
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<tr>
<td>17.15</td>
<td>Diagnostic biomarkers for ALS</td>
<td>R Bowser (USA)</td>
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</tbody>
</table>
Saturday 11 December 2010

SESSION 5  Poster Session (1)
17.45 – 19.30  Poster Session and Wine Reception

POSTER THEMES
- Human cell biology and pathology
- Genetics
- Epidemiology
- In vivo experimental models
- In vitro experimental models
- Improving diagnosis, prognosis and disease progression

SESSION 6A  Translational Strategies
08.30 – 09.00  Plastic viruses: engineering nanoparticles for targeting the central nervous system – G Battaglia (UK)
09.00 – 09.30  Applying iPSC technology for motor neuron disease: A patient first drug discovery platform – B Strulovici (USA)

SESSION 6B  Epidemiology
08.30 – 09.00  Can we identify risk factors for ALS/MND? – E Beghi (Italy)
09.00 – 09.15  Epidemiology of ALS in the Netherlands 2006 – 2009 – M Huisman (Netherlands)
09.15 – 09.30  ALS phenotypic heterogeneity: evidence from a population-based study – A Chio (Italy)

09.30 – 10.00 COFFEE

Sunday 12 December 2010

SESSION 6A  Translational Strategies
10.00 – 12.30 Poster Session

POSTER THEMES
- Human cell biology and pathology
- Genetics
- Epidemiology
- In vivo experimental models
- In vitro experimental models
- Improving diagnosis, prognosis and disease progression

SESSION 6B  Epidemiology
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09.00 – 09.15  Epidemiology of ALS in the Netherlands 2006 – 2009 – M Huisman (Netherlands)
09.15 – 09.30  ALS phenotypic heterogeneity: evidence from a population-based study – A Chio (Italy)

12.30 – 14.00 LUNCH
Sunday 12 December 2010

SESSION 8A  Genetics and Genomics

14.00 – 14.30  Clinical pathological and genetic features of amyotrophic lateral sclerosis associated with optineurin mutations
  – R Kaji (Japan)

14.30 – 14.45  A large CNV association study in sporadic ALS
  – H Blauw (Netherlands)

14.45 – 15.00  Rare mutations in angiogenin confer large risk for sporadic ALS
  – M Van Es (Netherlands)

15.00 – 15.15  Paraoxonase gene mutations in amyotrophic lateral sclerosis
  – N Ticozzi (Italy)

15.15 – 15.30  Juvenile ALS with basophilic inclusions in a FUS proteinopathy
  with FUS mutations – D Bäumer (UK)

SESSION 8B  Cognitive and Psychological Assessment and Support

14.00 – 14.15  Social cognition in ALS: impaired cognitive and affective theory of mind – S Abrahams (UK)

14.15 – 14.30  The nature of language deficits in ALS: semantic impairments in action sequencing – E van der Hulst (UK)


14.45 – 15.00  Diagnostic validity of the ALS cognitive behavioural screen – B Rush (USA)

15.00 – 15.15  Longitudinal cognitive screening using the ALS cognitive behavioural screen (ALS-CBSTM) – S Woolley (USA)

15.15 – 15.30  Computerized frontal assessment of amyotrophic lateral sclerosis – B Polletti (Italy)

SESSION 8C  Clinical Trials

14.00 – 14.30  Essentials of phase 2 clinical trial design – B Ravina (USA)

14.30 – 15.00  The ‘small’ clinical trial: challenges in design and interpretation of results – M McDermott (USA)

15.00 – 15.15  Comparing Endpoints: Slope of ALSFRS-R has greater power than time to lose 6 points – D Moore (USA)

15.15 – 15.30  Analysis of functional scores data in a study of dexpramipexole for Amyotrophic Lateral Sclerosis (ALS) in the context of non-trivial discontinuations and deaths – D Archibald (USA)

15.30 – 16.00 COFFEE
### SESSION 9A  Axonal Function and Pathology

<table>
<thead>
<tr>
<th>Time</th>
<th>Presentation</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.00</td>
<td>Axon degeneration mechanisms: new insights for selective vulnerability of motor units in ageing and disease</td>
<td>M Coleman (UK)</td>
</tr>
<tr>
<td>16.30</td>
<td>Cellular transport dysfunction in SOD1G93A transgenic mice and NSC34 cells</td>
<td>J Atkin (Australia)</td>
</tr>
<tr>
<td>16.45</td>
<td>In vitro model systems for NMJ formation utilizing motor neurons from adult rat, mouse and SOD1 transgenic mouse</td>
<td>J Hickman (USA)</td>
</tr>
<tr>
<td>17.00</td>
<td>Increased rate of maturation of electrical properties of SOD1 motor neurons</td>
<td>K Quinlan (USA)</td>
</tr>
<tr>
<td>17.15</td>
<td>Assessing motor neuron loss in the ALS rat with electrical impedance myography</td>
<td>S Rutkove (USA)</td>
</tr>
<tr>
<td>17.30</td>
<td>Evidence of early somato-dendritic alterations in lumbar motor neurons of SOD1 juvenile mice</td>
<td>J Durand (France)</td>
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### SESSION 9B  International Perspectives on Care Practice

<table>
<thead>
<tr>
<th>Time</th>
<th>Presentation</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.00</td>
<td>Palliative Care: access to services and support for providers</td>
<td>R Harris (Australia)</td>
</tr>
<tr>
<td>16.15</td>
<td><a href="http://www.ALShome.de">www.ALShome.de</a>: web-based self assessment of symptoms in ALS</td>
<td>A Maier (Germany)</td>
</tr>
<tr>
<td>16.30</td>
<td>Voice banking to facilitate compliance with speech generating augmentative communication</td>
<td>E Singleton (USA)</td>
</tr>
<tr>
<td>16.45</td>
<td>Amyotrophic lateral sclerosis patients' self reported satisfaction with assistive technology</td>
<td>K Gruis (USA)</td>
</tr>
<tr>
<td>17.00</td>
<td>‘The Dr said MND wouldn't affect my sexuality... but it has’</td>
<td>B Taylor (UK)</td>
</tr>
<tr>
<td>17.15</td>
<td>The nation's first ALS Green House® nursing home residence: a technological approach to care</td>
<td>B Berman (USA)</td>
</tr>
</tbody>
</table>

### SESSION 9C  Clinical Trials

<table>
<thead>
<tr>
<th>Time</th>
<th>Presentation</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.00</td>
<td>More power to you: Impact of trial design on adherence and outcome</td>
<td>M Cudkowicz (USA)</td>
</tr>
<tr>
<td>16.30</td>
<td>Modifiable barriers to enrolment in American ALS research studies</td>
<td>R Bedlack (USA)</td>
</tr>
<tr>
<td>16.45</td>
<td>Results of a clinical trial of talampanel in patients with ALS</td>
<td>J Shefner (USA)</td>
</tr>
<tr>
<td>17.00</td>
<td>Phase II study of pioglitazone in ALS</td>
<td>A Ludolph (Germany)</td>
</tr>
<tr>
<td>17.15</td>
<td>Discussion</td>
<td></td>
</tr>
</tbody>
</table>
## SESSION 10A Glial Cell Biology

**08.30 – 09.00** Mechanisms and therapy in ALS: Glia as determinants of disease progression – D Cleveland (USA)

**09.00 – 09.15** Gene expression profiling of astrocytes in pre-symptomatic G93A SOD1 mice reveals dysfunction in the astrocyte-motor neuron lactate shuttle – L Ferraiuolo (UK)

**09.15 – 09.30** Comprehensive genetic analysis of adult reactive astrocytes in rodent model (SOD1 G93A) of ALS reveals massive molecular reorganisation in vivo – Y Yang (USA)

**09.30 – 09.45** Monocarboxylic transporter (MCT1) BAC reported and over expresser mice as tools to reveal novel glial pathogenesis in ALS – Y Lee (USA)

**09.45 – 10.00** Focal in vivo transplantation of mutant SOD1 GRP-derived astrocytes influences wildtype motor neuron vulnerability – N Maragakis (USA)

### 10.00 – 10.30 COFFEE

## SESSION 11A Cell Biology and Pathology

**10.30 – 11.00** Novel RNA binding proteins in ALS – A Gitler (USA)

**11.00 – 11.15** Mechanisms of ALS resistance in motor neurons of oculomotor and Onuf’s nuclei – A Kaplan (USA)

**11.15 – 11.30** Intercellular misfolding of human wtSOD1 propagated in vitro – N Cashman (Canada)

**11.30 – 11.45** ALS mutations in FUS are clustered in the nuclear localization sequence and induce stress granules – H Zhu (USA)

**11.45 – 12.00** Mutant FUS proteins that cause amyotrophic lateral sclerosis incorporate into stress granules – L Hayward (USA)

**12.00 – 12.15** The H63D HFE gene variant reduces survival and disease duration in SODG93A mice – W Nandar (USA)

**12.15 – 12.30** p-TDP-43 increase in sporadic amyotrophic lateral sclerosis is associated with cellular stress: role of mitochondria – V Ayala (Spain)

**12.30 – 12.45** Repetitive nerve stimulation transiently opens the mitochondrial permeability transition pore in motor nerve terminals of symptomatic mutant SOD1 mice – E Barrett (USA)

## SESSION 10B Holistic Care

**08.30 – 09.00** Practical implications of genetics in ALS for patients and families – N Siddique (USA)

**09.00 – 09.15** Telemedicine to facilitate ALS research – M Benatar (USA)

**09.15 – 09.30** Identifying the needs of the ALS/FTD caregiver: development, implementation and evaluation of a clinical assessment instrument – A Brothers (USA)

**09.30 – 09.45** Identifying needs and interventions to support caregivers of patients with ALS – H Stephens (USA)

**09.45 – 10.00** A randomized controlled trial of physical activity in individuals with ALS: preliminary experience and short term follow up results of treatment with different exercise protocols – C Lunetta (Italy)

## SESSION 11B Respiratory and Nutritional Management

**10.30 – 11.00** Predicting energy needs in ALS: results of the ALS nutrition/NIPPV study – E Kasarskis (USA)

**11.00 – 11.15** Non-invasive ventilation in ALS: a 10 year population-based study in Italy – A Chiò (Italy)

**11.15 – 11.30** Risks of respiratory failure, emergency hospitalizations and unplanned outcomes of ALS/MND patients: a 20 year study – P Cazzolli (USA)

**11.30 – 11.45** Sleep characteristics and their predictive value in ALS – S Patel (USA)

**11.45 – 12.00** The role of airway clearance versus hypoventilation and respiratory muscle fatigue in ALS – E Tiryaki (USA)

**12.00 – 12.15** Using lung volume recruitment therapy to improve swallowing and airway protection for individuals with ALS – S Cleary (Canada)

**12.15 – 12.30** Final analysis of pilot trial of diaphragm pacing (DP) in ALS/MND with long term follow-up. No safety concerns and DP positively affects diaphragm respiration – R Onders (USA)
Travel Information

AIRPORT

From Orlando International Airport:
General airport information, including details of transport for people living with a disability, please visit the below websites:
Website: www.orlandoairports.net/
Transport for people with a disability: www.orlandoairports.net/ops/disabled.htm

Bus Stations:
- Located on the A-side of the Main Terminal, on the Ground Transportation Level (Level 1), at Commercial Lane spaces A38-A41

Taxi Cabs:
- Ace Metro/Luxury Cab: Tel: (407) 855-1111
- Diamond Cab Company: Tel: (407) 523-3333
- Quick Cab: Tel: (407) 447-1444
- Star Taxi: Tel: (407) 857-9999
- Town & Country Transport: Tel: (407) 828-3035
- Yellow/City Cab: Tel: (407) 422-2222

Taxis may carry up to nine passengers, and charge the same rate regardless of the number of passengers. Metered rate may vary from the approximate rates quoted above.

Taxis are available on both the A and B sides of the main terminal, on the ground transportation level (level 1), and at Commercial Lane parking spaces: A5-A8 and A28-A31, B5-B8 and B19-B24.

Shuttle Vans:
Mears Transportation Group, Tel: (407) 423-5566: Shuttle van fares are charged per person. Check with the attendant for round-trip fares and children's rates. Shuttle vans are available on both the A and B sides of the main terminal, on the ground transportation level (level 1), and at the Commercial Lane parking spaces:A9-A10 and A36-A37, B9-B10 and B40-B41.

There is a shuttle bus from the airport to the hotel, run by Mears Transportation. Booking is advisable for this service via their website: https://secure.mearstransportation.com

General Transport Costs

The prices are correct at time of publication.

<table>
<thead>
<tr>
<th>Destination</th>
<th>Local Bus</th>
<th>Shuttle Van</th>
<th>Taxi</th>
<th>Limousine</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>per person one way</td>
<td>round trip per trip/one way</td>
<td>per hour All destinations</td>
<td></td>
</tr>
<tr>
<td>International Drive</td>
<td>$2</td>
<td>$18</td>
<td>$29</td>
<td>$33 - $39</td>
</tr>
<tr>
<td>Downtown Orlando</td>
<td>$2</td>
<td>$17</td>
<td>$28</td>
<td>$35</td>
</tr>
<tr>
<td>Winter Park/Maitland</td>
<td>$2</td>
<td>$20</td>
<td>$33</td>
<td>$35</td>
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<tr>
<td>Lake Buena Vista</td>
<td>$2</td>
<td>$26</td>
<td>$45</td>
<td>$43 - $75</td>
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<td>Kissimmee</td>
<td>$2</td>
<td>$20</td>
<td>$33</td>
<td>$47 - $52</td>
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<tr>
<td>Disney (maingate)</td>
<td>$4</td>
<td></td>
<td></td>
<td>$55</td>
</tr>
<tr>
<td>Walt Disney World</td>
<td>$4</td>
<td></td>
<td></td>
<td>$60</td>
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<tr>
<td>Port Canaveral</td>
<td>N/A</td>
<td></td>
<td></td>
<td>$105</td>
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</tbody>
</table>

Local Buses
(From airport)

Downtown Orlando (Approximately 40 minutes)
- Lynx bus 11 departs via Orange Avenue at 5:56 to 23:57 (5:56 to 21:57 on Saturdays, and 6:27 to 20:27 Sundays and holidays)
- Lynx bus 51 departs via Conway at 5:38 to 21:37 (5:20 to 20:22 on Sundays and holidays)

International Drive (Approximately 60 minutes)
- Lynx bus 42 departs at 6:00 to 22:30 (6:30 to 21:30 on Sundays and holidays)

Walt Disney World (Approximately 75 minutes)
- Lynx bus 111 departs at 6:00 to 22:30 (6:30 to 21:30 on Sundays and holidays)

Apopka
- Lynx bus 41 departs via SR 436 at 5:15 to 22:45 (5:40 to 21:40 on Sundays and holidays)

Additional connecting service to shopping and residential areas also available. Please see the www.golynx.com/ web site for more details including the complete schedule.
Florida is not all about theme parks! Of course, it is the theme park capital of the world and the crowds come for Disney, Universal and Seaworld, but step away from the thrilling atmosphere of the parks and you will find a different vibe instantly.

Orlando is the central hub of all the action, where you will find many mini-resorts. Lake Buena Vista, Kissimmee, International Drive are to name but a few. A stay in one of these areas means you will be perfectly placed for all of the attractions, but a short drive north and you will discover the real Orlando, with its business district, history and plenty of good restaurants and bars. Orlando has also matured into a vivid cultural destination, from the visual and performing arts, to museums, parks and gardens.

Cape Canaveral, and the world-famous Kennedy Space Center, are 45 minutes east of Orlando. The city of Cape Canaveral is a few miles south of the Cape - Mosquito Lagoon, The Indian River, Merritt Island National Wildlife Refuge and Canaveral National Seashore are also features of this area.

Head west and idyllic beaches await you at St Petersburg, Clearwater and Tampa. Further south you will find chic Naples and the Everglades National Park, home to wildlife such as the manatee and American alligators and crocodiles! At the southernmost tip of Florida are the Keys, a haven for diving enthusiasts and those who love the laid back lifestyle.

Florida is also the world leader in golfing terms – there are over 1,000 courses, many of which feature prominently in the lists of America's best.

Orlando International Airport is easily accessible and within 15 miles of major attractions, meeting facilities and downtown Orlando. Taxi and limousine services can take you anywhere in the Greater Orlando area, while the city's Lynx bus system provides economical public transport around Orlando. Bus stops are marked with a ‘paw’ print of a Lynx cat but if you fancy returning to the horse-and-buggy days, carriage rides are also available through local vendors in downtown Orlando.

**Orlando Information:**
www.orlandoinfo.com/attractions/
www.lonelyplanet.com/usa/florida/orlando
www.orlandofloridaguide.com

**Hotel Information:**
www.grandelakes.com
VENUE
JW Marriott Orlando
Grande Lakes
4040 Central Florida Parkway
Orlando, FL 32837
USA
Tel: (407) 393 4406
website: www.grandelakes.com

Taking advantage of the ALS/MND Symposium special rates:
To reserve accommodation at the venue please visit the website below

Alternatively you can contact the hotel on (00) 1-800-576-5760 and quote the group code mndmnda

Rates are as follows:
Single/double room $167.00 per night (excluding tax)

The hotel is located 10 miles from the nearest train station, Orlando Amtrack, and 10 miles from Orlando International; Orlando Sanford airport is 40 miles. There is a shuttle bus from each airport to the hotel, run by Mears Transportation. Booking is advisable for this service via their website, https://secure.mearstransportation.com
General Information and General Conditions of Registration

MONEY
Orlando’s currency is the US Dollar ($). 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.

VISA REQUIREMENTS
Visitors to Orlando should visit the below website for visa requirements:
https://esta.cbp.dhs.gov

TIME ZONE
Orlando is five hours behind Greenwich Mean Time (GMT).

ELECTRICAL CURRENTS
The electrical current in Orlando 120V and 60Hz therefore visitors may need an adapter and/or transformer for electrical appliances.

WEATHER
The winter months of December, January and February generally provide the most pleasant temperatures in the Orlando area. Humidity can still be on the higher side and rainfall is at a minimum. Average temperatures are 73°F or 23°C.

EMERGENCY SERVICES IN ORLANDO
Dial 911 to connect to Orlando emergency services for fire, police, or ambulance.

ORLANDO TOURIST INFORMATION SITE
http://orlandotouristinformationbureau.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 organisers.

CERTIFICATE OF ATTENDANCE
Certificates of Attendance will be provided for participants.

General Conditions of Registration

1 It is expressly agreed that the Motor Neurone Disease Association UK, Programme Committee and the Conference Secretariat for the 21st 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 21st 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 21st 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 of 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 the sole discretion and shall be final.

CANCELLATION POLICY
Symposium Registration Fees: Refunds of Conference registration fees paid, less a 10% administration fee, will be granted until 26 November 2010. Cancellation must be received in writing by The Conference Team, MND Association UK before this date. NO REFUNDS WILL BE ISSUED AFTER THIS DATE.
MISSION STATEMENT;

To stimulate improvement in quality of life for people living with ALS/MND, scientific innovation and exchange of information

EARLY ANNOUNCEMENT

22nd INTERNATIONAL SYMPOSIUM ON ALS/MND
30 November – 2 December 2011
Hilton Hotel, Sydney, Australia