16th INTERNATIONAL SYMPOSIUM ON ALS/MND

8 - 10 December 2005
Dublin, Republic of Ireland

Host:
The Irish Motor Neurone Disease Association

Organised by the MND Association
in co-operation with the International Alliance of ALS/MND Associations
**THURSDAY 8 DECEMBER**

**Location:** Lansdowne & Pembroke Room

### SESSION 1

**JOINT OPENING SESSION**

**Chairs:** P Shaw (UK)  O Hardiman (Ireland)

- **08.30-08.35** Welcome and Introduction
- **08.35-09.20** Alternative medicine – hope or hype? – S Barrett (USA)
- **09.20-10.00** Phenotypic variation in motor neuron disease – N Leigh (UK)

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### 10.00-10.30 COFFEE

### SESSION 2A

**MOTOR NEURON BIOLOGY & PATHOLOGY**

**Chairs:** D Figlewicz (USA)  M Rattray (UK)

- **10.30-11.00** Pathological variation in motor neuron disease – P Ince (UK)
- **11.00-11.15** Is there a causal role of steryl glucoside neurotoxins in ALS? – J Wilson (Canada)
- **11.15-11.30** Mutant heat-shock protein 27 results in the selective aggregation of specific cellular components – K Talbot (UK)
- **11.30-11.45** Heat-shock response, but not HSP27, prevents mutant SOD1-dependent cell death in a culture model of ALS – J Krishnan (Belgium)
- **11.45-12.00** Onset administration of Motexafin Gadolinium extends survival in G93A mice; possible role of increased zinc occupancy – J Crow (USA)
- **12.00-12.15** GluR2 deficiency accelerates motor neuron degeneration in a mouse model of ALS – P Van Damme (Belgium)
- **12.15-12.30** Altered excitability of cortical neurons in a transgenic model of familial ALS – C Zona (Italy)

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### 12.30-14.00 LUNCH

### SESSION 2B

**CLINICAL TRIALS & TRIAL DESIGN**

**Chairs:** M Cudkowicz (USA)  L Van den Berg (Netherlands)

- **10.30-10.45** Phase II/III controlled trial of TCH346 in patients with ALS – R Miller (USA)
- **10.45-11.00** Safety, tolerability and pharmacokinetics of AEOL 10150 in ALS – R Miller (USA)
- **11.00-11.15** Multi-center clinical trial of creatine monohydrate in patients with ALS – J Rosenfeld (USA)
- **11.15-11.30** Randomized controlled phase II trial of glatiramer acetate (Copaxone) in ALS – P Gordon (USA)
- **11.30-11.45** Novel phase II design for clinical trials of ALS using selection paradigm and group sequential analysis – P Gordon (USA)
- **11.45-12.00** New phase II designs to improve clinical trials in ALS – D Moore (USA)
- **12.00-12.15** Clinical trials in ALS can be shortened by selecting rapidly progressing patients – M De Carvalho (Portugal)
- **12.15-12.30** Predicting rate of disease progression using percent of predicted normal strength in ALS clinical trial design – P Andres (USA)
### THURSDAY 8 DECEMBER

#### SESSION 3A
**Location:** Lansdowne & Pembroke Room  
**Chairs:** V Silani (Italy) G Sobue (Japan)

<table>
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<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>14.00-14.30</td>
<td>Distal hereditary motor neuropathies: clinical and molecular genetic aspects</td>
<td>P de Jonghe (Belgium)</td>
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<tr>
<td>14.30-15.00</td>
<td>Spinal muscular atrophy</td>
<td>M Sendtner (Germany)</td>
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<tr>
<td>15.00-15.30</td>
<td>Experimental enhancement of axonal regeneration, compensatory neurite outgrowth and functional recovery in the adult injured mammalian spinal cord</td>
<td>M Schwab (Switzerland)</td>
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#### Session 3B
**Location:** Herbert Room  
**Chairs:** G Borasio (Germany) H Mitsumoto (USA)

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<tr>
<td>14.00-14.30</td>
<td>New approaches to palliative care</td>
<td>C Normand (Ireland)</td>
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<tr>
<td>14.30-15.00</td>
<td>Determining quality of life in ALS/MND</td>
<td>C O’Boyle (Ireland)</td>
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<td>15.00-15.30</td>
<td>‘Affirming life preparing for death’: dual challenges in addressing quality of life for people with MND</td>
<td>A Claffey (Ireland)</td>
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#### 15.30-16.00 COFFEE

#### SESSION 4A
**Location:** Lansdowne & Pembroke Room  
**Chairs:** C Miller (UK) A Grierson (UK)

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<tr>
<th>Time</th>
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<tr>
<td>16.00-16.30</td>
<td>Axonal transport in health and disease</td>
<td>A Grierson (UK)</td>
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<td>16.30-16.45</td>
<td>Quantification of axonal mitochondrial transport in motor neuron disease</td>
<td>K De Vos (UK)</td>
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<td>16.45-17.00</td>
<td>ALS mutant SOD1 disrupts both fast and slow axonal transport</td>
<td>M Tennant (UK)</td>
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<td>17.00-17.15</td>
<td>ALS2CL, a novel ALS2 interacting protein, modulates ALS2-mediated endosomal dynamics</td>
<td>S Hadano (Japan)</td>
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<td>17.15-17.30</td>
<td>Neuronal expression of an ALS-associated mutant (Dynactin P150GLUED) in mice causes motor neuron disease</td>
<td>F Laird (USA)</td>
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#### Session 4B
**Location:** Herbert Room  
**Chairs:** G Mora (Italy) T Heiman-Patterson (USA)

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<thead>
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<tr>
<td>16.00-16.15</td>
<td>Types of oesophageal body peristalsis in ALS patients with dysphagia</td>
<td>B Tomik (Poland)</td>
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<tr>
<td>16.15-16.30</td>
<td>Assessing and predicting successful tube placement outcomes in ALS patients</td>
<td>K Beggs &amp; M Choi (Canada)</td>
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<td>16.45-17.00</td>
<td>Enhancing PEG tube placement: a new device for maintaining respiratory function during endoscopy in ALS patients</td>
<td>T Pacicco (USA)</td>
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<td>17.00-17.30</td>
<td>Does rehabilitation make sense in ALS/MND?</td>
<td>C Ward (UK)</td>
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#### 19.30 Drinks Reception and Gala Dinner with Presentation of International Alliance Awards
**FRIDAY 9 DECEMBER**

**SESSION 5  POSTER SESSION**

08.30-11.00 Presenters will attend their posters, in allocated 30-minute slots as detailed below.

**POSTER THEMES**

1. **Human Cell Biology & Pathology** (10.00-10.30)
2. **Genetics and Epidemiology** (09.30-10.00)
3. **In vivo Experimental Models** (09.00-09.30)
4. **In vitro Experimental Models** (08.30-09.00)
5. **Improving Diagnosis and Prognosis in Motor Neuron Diseases** (10.00-10.30)
6. **Imaging, Electrophysiology and Markers of Disease Progression** (09.00-09.30)
7. **Respiratory and Nutritional Management** (08.30-09.00)
8. **Cognitive & Psychological Assessment and Support** (09.30-10.00)
9. **Research to Improve Standards of Care** (09.00-09.30)
10a. (SW) **Scientific Work in Progress** (09.30-10.00)
10b. (CW) **Clinical Work in Progress & Care Practice** (08.30-09.00)

**FRIDAY 9 DECEMBER**

**SESSION 6A INFLAMMATION**

**Chairs:**  
*W Robberecht* (Belgium)  
*S Appel* (USA)

11.30-11.45 Activated microglia in ALS: a double-edged sword – *S Appel* (USA)

11.45-12.00 Microglial activation in CX3CR1 null-SOD1(G93A) ALS mice worsens disease phenotype – *E Pioro* (USA)

12.00-12.15 Transcriptional regulation of inflammatory processes in ALS: expression of CCAAT/Enhancer Binding Protein (C/EBP) β, suppressors of cytokine signalling (SOCS) and interferon regulatory factor-1 (IRF-1) – *J Anneser* (Germany)

12.15-12.30 Definition of a transcriptional signature of peripheral myeloid cells associated with severe neurodegenerative disease – *K Hadlock* (USA)

**SESSION 6B CLINICAL PHENOTYPES**

**Chairs:**  
*C Desnuelle* (France)  
*M Swash* (UK)

11.30-11.45 Regional differences between long and short survivors in ALS – *J Katz* (USA)

11.45-12.00 Kennedy’s disease: a clinical and functional study in 44 patients – *F Salachas* (France)

12.00-12.15 Early-onset ALS with spastic phenotype: a distinct entity? – *M Sabatelli* (Italy)

12.15-12.30 Further insights into HSP and spastin: severe complicated phenotypes, double mutations and evidence of lower motor neuron dysfunction – *C McDermott* (UK)

**11.00-11.30 COFFEE**

**12.30-14.00 LUNCH**
FRIDAY 9 DECEMBER

SESSION 7A PROTEIN FOLDING AND DEGRADATION DEFECTS

Chairs: C Shaw (UK) L Van den Bosch (Belgium)

14.00-14.45 Functions of the proteasome in cell regulation and neuromuscular disease – H Durham (Canada)

14.45-15.00 Role of dysfunction of the ubiquitin proteasome pathway in the mechanisms of motor neuron degeneration in a mouse model of ALS – C Cheroni (Italy)

15.00-15.15 The role of endoplasmic reticulum (ER) stress and the unfolded protein response (UPR) in ALS – J Atkin (Australia)

15.15-15.30 Monomeric/misfolded SOD1 detected in mouse models of ALS using a designed antibody – A Chakrabartty (Canada)

SESSION 7B CARER SUPPORT

Chairs: T Holmes (UK) D Forshew (USA)

14.00-14.30 The impact of motor neuron disease on carers and their experience of service provision: a systematic review and development of a disease specific questionnaire – C Mockford (UK)

14.30-14.45 The impact of enteral nutritional support on the quality of life of ALS patients and their primary caregivers – B O’Farrell (Canada)

14.45-15.00 Caregiver time use: a pilot study in ALS – A Chio (Italy)

15.00-15.15 Engaging social support systems to improve quality of life for patients and carers – R Ray (Australia)

15.15-15.30 Atypical features in patients with ALS and their impact on caregiver burden: findings from the ALS Patient CARE Database – E Pioro (USA)

SESSION 7C IMAGING AND NEUROPHYSIOLOGY

Chairs: W Bradley (USA) M Weber (Switzerland)

14.00-14.15 Statistical motor unit number estimation and ALS trials: the effect of motor unit instability – J Shefner (USA)

14.15-14.30 Evidence for cortical dysfunction in ALS: results of an MEG study – R Boyajian (USA)

14.30-14.45 Imaging in patients with pure and complicated hereditary spastic paraparesis: 3-D MRI morphometry of the brain and upper spinal cord planimetry – J Kassubek (Germany)

14.45-15.00 Development of upper motoneuron involvement in ALS: a longitudinal MRI study using diffusion tensor imaging and voxel-based morphometry – J Grosskreutz (Germany)

15.00-15.15 Quantitative evaluation of FLAIR-MR images correlates to spasticity score but not to cortical excitability – M Hecht (Germany)

15.15-15.30 Impaired cardiovagal and increased vasomotor responses in early-stage ALS – J Gutierrez (Cuba)

15.30-16.00 COFFEE
Location: Connaught Room (Second Floor)

SESSION 8C GENETICS

Chairs: P Andersen (Sweden) T Siddique (USA)

16.00-16.30 The genetics of motor neuron disease: where are we now? – A Al-Chalabi (UK)

16.30-16.45 Spastin mutations in sporadic adult onset upper motor neuron syndromes – F Brugman (Netherlands)

16.45-17.00 VAPB mutations in ALS – P Valdmanis (Canada)

17.00-17.15 Segregation of tau haplotype in ALS – M Greenway (Ireland)

17.15-17.30 Increased incidence of the HFE H63D variation, but not of C282Y and C65S in sporadic ALS patients of Italian origin – A Chio (Italy)

17.30-17.45 A novel locus on chromosome 9p for familial MND and FTD identified using microarray SNP genotyping – C Vance (UK)
**S A T U R D A Y  1 0  D E C E M B E R**

**SESSION 9A**  
**Location:** Lansdowne & Pembroke Room  
**MITOCHONDRIA: BIOENERGETICS & CELL DEATH**  
**Chairs:**  
J Prehn (Ireland)  
D Wallace (USA)  

**08.30-09.00**  
A mitochondrial paradigm for age-related metabolic and degenerative diseases –  
D Wallace (USA)  

**09.00-09.30**  
Regulation of mitochondrial and endoplasmic reticulum cell death pathways –  
J Prehn (Ireland)  

**09.30-09.45**  
Impaired mitochondrial anti-oxidant defence in SOD1-related familial ALS –  
C Wood-Allum (UK)  

**09.45-10.00**  
CNS metabolic defects precede pathological alterations in a mouse model of familial ALS –  
S Browne (USA)  

**SESSION 9B**  
**Location:** Herbert Room  
**POPULATION GENETICS & EPIDEMIOLOGY**  
**Chairs:**  
O Hardiman (Ireland)  
A Chio (Italy)  

**08.30-09.00**  
An introduction to complex genetics: pitfalls in identifying disease susceptibility in sporadic populations –  
K Merikangas (USA)  

**09.00-09.30**  
Epidemiology and ethnic diversity in ALS -  
O Hardiman (Ireland)  

**09.30-09.45**  
Different ‘Down Under’? Motor neuron disease in the Southern Hemisphere –  
R Pamphlett (Australia)  

**09.45-10.00**  
Structured interview for genetic and environmental risk factors in ALS and its test-retest reliability evaluation –  
H Mitsumoto (USA)  

**10.00-10.30 COFFEE**

**S A T U R D A Y  1 0  D E C E M B E R**

**SESSION 10A**  
**Location:** Lansdowne & Pembroke Room  
**ANIMAL MODELS**  
**Chairs:**  
C Bendotti (Italy)  
J Glass (USA)  

**10.30-11.00**  
Mice- how they help us study motor neuron degeneration –  
E Fisher (UK)  

**11.00-11.15**  
Identification of modifier genes that can delay disease onset in a mouse model for ALS using genetic mapping and gene expression profiling –  
P Van Vught (Netherlands)  

**11.15-11.30**  
The role of alsin in juvenile onset ALS –  
R Devon (UK)  

**11.30-11.45**  
Development of an alsin knockout mouse model –  
H Deng (USA)  

**11.45-12.00**  
Motor co-ordination and learning deficits, increased anxiety and susceptibility to oxidative stress in mice lacking ALS2 –  
H Cai (USA)  

**12.00-12.30**  
Zebrafish as a model of motoneuron diseases –  
C Beattie (USA)  

**SESSION 10B**  
**Location:** Herbert Room  
**RESPIRATORY MANAGEMENT**  
**Chairs:**  
T Williams (UK)  
D McKim (Canada)  

**10.30-11.00**  
‘New uses for old bags’: multidisciplinary respiratory care in ALS –  
D McKim (Canada)  

**11.00-11.15**  
Predictors of non-invasive ventilation tolerance in patients with ALS –  
K Gruis (USA)  

**11.15-11.30**  
Earlier use of non-invasive ventilation may prolong survival in subjects with ALS –  
N Lechtzin (USA)  

**11.30-11.45**  
Prognosis of ALS with respiratory onset –  
C Shoesmith (Canada)  

**11.45-12.00**  
Respiratory rate is strongly predictive of hypercapnia and shorter survival in ALS –  
A Calvo (Italy)  

**12.00-12.15**  
A randomized, controlled trial of high frequency chest wall oscillation in ALS –  
D Lange (USA)  

**12.15-12.30**  
A retrospective evaluation of high frequency chest wall oscillation therapy in patients with ALS/MND –  
C Jackson (USA)  

**12.30 - 14.00 LUNCH**
SATURDAY 10 DECEMBER

Location: Lansdowne & Pembroke Room

SESSION 11  JOINT CLOSING SESSION

Chairs:  P Shaw  (UK)  Y Itoyama  (Japan)

14.00-14.10  The International Alliance of ALS/MND Associations - R Harris  (Australia)

14.10-14.30  Symposium Highlights: Clinical – G D Borasio  (Germany)

14.30-14.50  Symposium Highlights: Scientific - L Greensmith  (UK)

14.50-15.30  From mind to movement: neurotechnologies to reconnect the brain to the world – J Donoghue  (USA)

15.50  Closing remarks

EXHIBITORS
Exhibitors’ stands will be on display from Thursday 8 December:

International Alliance of ALS/MND Associations
ALS Association
Irish MND Association
MND Association
Toby Churchill
Taylor & Francis
Rolltalk, Norway
Promedics Ltd
J H Emerson

Thank you to the following organisations for supporting the 16th International Symposium on ALS/MND.

Diageo

Ono Pharma
Wednesday 7 December 2005

Registration All Events
Speaker Room
Allied Professionals' Forum
Refreshments
Lunch
Exhibitors
European FALS/ALS Meeting
WALS Group Meeting
ALS Care Meeting
WFN Meeting
ALS Research Group
Programme Committee Meeting
Reception
Appian
Herbert Room
Buck Mulligans Bar
Sussex Restaurant/Mespil Bar
Concourse
Connaught
Adelaide
Elgin
Connaught
Adelaide

Thursday 8 December 2005

Registration All Events
Speaker Room
16th International Symposium
Joint Opening Session 1
Scientific Sessions 2A/3A/4A
Clinical Sessions 2B/3B/4B
Exhibitors
Poster Session
Refreshments
Lunch
Pre Dinner Drinks
Gala Dinner
Reception
Appian
Lansdowne/Pembroke Room
Lansdowne/Pembroke Room
Herbert Room
Ulster/Munster/Leinster Rooms
Buck Mulligans Bar
Club Anabels/Sussex Restaurant
Buck Mulligans Bar
Fitzwilliam Suite

Friday 9 December 2005

Registration All Events
Speaker Room
ALS Journal Breakfast Meeting
NE Consortium Breakfast Meeting
Poster Session 5
Exhibitors
Refreshments
Scientific Sessions 6A/7A/8A
Clinical Sessions 6B/7B/8B
Lunch
Alternative Sessions 7C/8C
Cochrane Group Meeting
Nurses Forum/Multidisciplinary
Reception
Appian
Connaught 1
Connaught 2
Ulster/Munster/Leinster Rooms
Concourse
Buck Mulligans Bar
Lansdowne/Pembroke Room
Herbert Room
Club Anabels/Sussex Restaurant
Connaught
Adelaide
Herbert Room

Saturday 10 December 2005

Speaker Room
Programme Committee Meeting
Minocycline Trial Investigator Meeting
Scientific Sessions 9A/10A
Clinical Sessions 9B/10B
Poster Session
Exhibitors
Refreshments
Lunch
Joint Closing Session 11
Appian
Clyde
Elgin
Lansdowne/Pembroke Room
Herbert Room
Ulster/Munster/Leinster Rooms
Concourse
Buck Mulligans Bar
Club Anabels/Sussex Restaurant
Lansdowne/Pembroke Room

Sunday 11 December 2005

EUALS Meeting
Ulster Room

MEETING ROOM LOCATIONS

The Burlington Hotel,
Dublin, Ireland -

The Burlington Hotel,
Dublin, Ireland -
MISSION STATEMENT;
To stimulate improvement in quality of life for people living with ALS/MND, scientific innovation and exchange of information

EARLY ANNOUNCEMENT

17th INTERNATIONAL SYMPOSIUM
ON ALS/MND
30 NOV - 2 DEC 2006
YOKOHAMA, JAPAN