



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

22nd Annual Meeting

Tuesday and Wednesday, 2-3 December 2014
Belgium I, II & III, Thon Hotel EU, Brussels, Belgium

AGENDA

TUESDAY, 2 DECEMBER 2014

- 08:45 1 Welcome & Introduction (30 min)
- 09:15 **Annual General Meeting** (45 min)
- 10:00 2 *Ice Bucket Challenge: Origins* (10 min)
 Rob Goldstein, ALS TDI, USA
- 10:10 3 *Ice Bucket Challenge: Open Discussion* (20 min)
- 10:30 **Morning Refreshments** (30 min)
- 11:00 **Fundraising** (45 minutes)
- 4 *Strategic Fundraising*
 Rod Harris, MND Victoria, Australia
- 5 *2000 Volunteers Are the Fundraising Pillar...*
 Jens Spanfelt, Muskelsvindfonden
- 6 *The Fundraising Program in Argentina*
 Pablo Aquino, ELA Argentina
- 11:45 **Awareness and Advocacy** (60 min)
- 7 *An Exciting Year for ALS Awareness in Italy*
 Christian Lunetta, AISLA Onlus, Italy
- 8 *The G.E.R.A.L.D.S. Network for Professionals*
 Martin Burger, ALS-Vereinigung.ch, Switzerland
- 9 *ALS Awareness in Japan in 2014 – Achievements and Difficulties*
 Yumiko Kawaguchi, Japan ALS Association (JALSA)
- 10 *Low Cost/High Quality: A National Awareness Campaign Based on Professional Partnerships*
 Francisco Tellechea Rotta, Instituto Paulo Gontijo (IPG), Brazil
- 12:45 **Lunch** (60 min)
- 13:45 **Challenges to Providing Services** (75 min)
- 11 *Red Flags for MND: A Step Towards Earlier Diagnosis and Efficient Referral*
 Steve Bell, The MND Association of England, Wales and N Ireland
- 12 *Overcoming Obstacles*
 Tatiana Mesquita e Silva, ABrELA, Brazil
- 13 *Cultural Challenges in ALS Care*
 Efrat Carmi, IsrALS, Israel

- 14 *Quality of Care and Compliance in PALS in Russia*
Gleb Levitsky, Russian Charity ALS Foundation
- 15 *Challenges to Providing Services*
Nicole Yarab, The ALS Association, USA
- 15:00 **Refreshments** (30min)
- 15:30 **Registries** (30 min)
- 16 *SMART – MND*
Craig Stockton, MND Scotland
- 17 *The Australian MND Registry: 10 Years On – Where to from Here?*
Janet Nash, MND Australia
- 16:00 **Partnerships Update** (30 min)
- 18 *Maximizing the Potential of Partnerships*
Kathy Mitchell, Canada
- 19 *Nordic Partnership*
Gudjon Sigurdsson, MND Association of Iceland
- 16:30 **Free Time**
- 18:30 **“Warm & Fuzzy” Dinner**

WEDNESDAY, 3 DECEMBER 2014

- 09:00 20 Overview of Strategic Plan 2012-15 and Report on 2014 Actions and Outcomes (30 min)
- 09:30 21 Workshop: Priorities & Working Groups for 2015 (60 min)
- 10:30 **Morning Refreshments** (30 min)
- 11:00 **Services** (75 min)
- 22 *A Pilot AAC Project*
Bob Bestow, MND Scotland
- 23 *The Development and Efficiency of the Support Group in Taiwan MND Association*
Yun-Ju Lin, Taiwan MND Association
- 24 *Help and Hope for PALS*
Wendy Abrams, Les Turner ALS Foundation, USA
- 25 *The Light That Will Never Dim*
Kiki Qu, Taiwan MND Association
- 26 *How NGOs Approach Government*
Thor Thorarinnsson, Welfare Ministry, Iceland
- 12:15 **Research Update** (30 min)
- 27 *Scientific & Research Update: Project MINE*
Dr. Leonard Van Den Berg, MD, PhD
- 12:45 **Invitation to Orlando 2015** (10 min)
The ALS Association, USA
- 12:55 **Thank You & Close: Meeting Adjourns**
- 13:05 Lunch (60 min)

- 14:30 "Ask the Experts"
16:30 "Ask the Experts" Reception
18:30 Dinner hosted by ALS Liga Belgie

Thanks to our generous host association.



Thanks to our 2014 sponsors, who made this event possible.

Platinum



Gold



Silver



Programme Committee

Efrat Carmi, IsrALS, Israel
Sara Feldman, The ALS Hope Foundation, USA
Dr. Alper Kaya, ALS-MNH Derneği, Turkey
Jens Spanfelt, Muskelsvindfonden, Denmark