



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

25th Annual Meeting
Tuesday and Wednesday, 5-6 December 2017
Marine Ballroom III-IV, Westin Boston Waterfront
Boston, MA, USA

TUESDAY, 5 DECEMBER

- 08:15 1 Welcome & Introduction (30 min)
- 08:45 **Annual General Meeting** (60 min)
- 09:45 2 Opening Remarks from the General Manager (15 min)
- 10:00 **Morning Refreshments** (30 min)
- 10:30 3 Welcoming Our New Members (15 min)
- 10:45 **Programming for PALS and CALS** (75 min)
- 4 *Ten Years of IPG in the International Alliance: Current Programmes and Future Directions*
Dr. Francisco Rotta, Instituto Paulo Gontijo (IPG)
- 5 *Spreading Hope One Child at a Time*
Jodi O'Donnell-Ames, Hope Loves Company
- 6 *ALS Care: Professional Counselling and Support at Home*
Martin Burger, ALS Schweiz
- 7 *Individualised ALS Support in the Home*
Judy Richman, Les Turner ALS Foundation
- 8 *A Revolutionary Home for PALS*
Barry Berman, Chelsea Jewish Foundation
- 12:00 **Lunch** (60 min)
- 13:00 **Programming for PALS and CALS continued** (75 min)
- 9 *Programming for Arab ALS Patients in Israel*
Efrat Carmi, IsrALS
- 10 *The Spanish National Health System: the World's Best Umbrella for PALS Care?*
Carlos Donestevé, FUNDELA
- 11 *ALS/MND Mobile App Launched: Info at the Tip of the Fingers*

Dr. Hemangi Sane, Asha Ek Hope Foundation

12 *MIXITON*

Christine Tabuenca, ARSLA

13 *Transforming MND Care Audit Tool*

Steve Bell, MND Association of England, Wales and N Ireland

14:15 **Partnerships and Collaborations** (45 min)

14 *UNELA: The First Latin American Organisation of ALS/MND Associations*

Pablo Aquino, Asociación ELA Argentina

15 *The Power of Yes: Moscow and St. Petersburg Live Now*

Kathleen Mitchell

16 *Mentoring: The Next Step in Partnership*

Rod Harris, MND Victoria (on behalf of the Partnership Committee)

15:00 **Refreshments** (30 min)

15:30 **Research and Science** (75 min)

17 *Beating ALS in the Most Generous Nation in the World*

Ruben Cauchi, ALS Malta

18 *TMNDA's Research Initiatives*

Kiki Qu, Taiwan MND Association

19 *Prize4Life: Infrastructure and Resources for ALS Research*

Iris Perl, Prize4Life

20 *Radicava: How Did US ALS Organisations Prepare for FDA Ruling and Speak with PALS/CALS After Approval?*

Rob Goldstein, ALS Therapy Development Institute

21 *Designing and Implementing an International Web-Based Questionnaire to Look at Risk Factors for ALS/MND*

Jane Parkin Kullman, ALS Quest

16:45 **Networking in Lobby** (60 min)

19:00 **"Warm & Fuzzy" Dinner** (Marine Ballroom I-II)

MONDAY, 5 DECEMBER 2016

09:00 22 Strategic Plan Presentation (30 min)

09:30 23 Strategic Planning Workshop (60 min)

10:30 **Morning Refreshments** (30 min)

11:00 **Organisational Development & Looking to the Future** (30 min)

24 "4+1" Grows Faster

Jin-Huan Wang, Beijing Oriental Rain ALS Care Centre (BORACC)

25 Strategic Planning for a Future without ALS/MND

Tammy Moore, ALS Canada

- 11:30 **Scientific Update with Dr. Jonathan Glass**
- 12:00 **Invitation to Glasgow 2018 (10 min)**
MND Scotland
- 12:10 **Thank You & Close: Meeting Adjourns (Group Photo)**
- 12:30 Lunch (60 min)
- 14:30 **"Ask the Experts"**
- 19:00 Host Dinner

Thank you to our generous co-hosts!



Thank you to our Platinum Sponsor!



Cytokinetix

Alliance Meeting Programme Committee

Efrat Carmi, IsrALS, Israel

Sara Feldman, The ALS Hope Foundation, USA

Tammy Moore, ALS Canada