

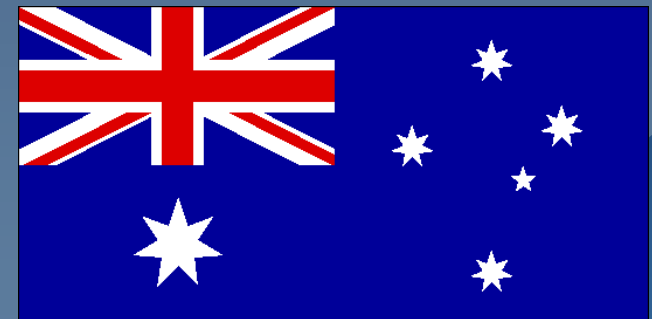
**International Alliance of ALS/MND
Associations**

19th Annual Meeting

Hilton Hotel

SYDNEY

November 2011





ATTENDANCE

- ◆ Very good- 79 Delegates /Observers (Last Year -96)
- ◆ Representing at least 19 Member Associations and guest come from 20 countries
- ◆ Apart from floor questions, we received presentations / contributions from the Platform by representatives of the Associations of 11 different countries on their experiences, challenges and successes



BOARD OF DIRECTORS

All Day Meeting to Consider Statutory Annual Reports and Accounts, Formal Resolutions and Other Strategic and Policy Issues

- ❑ 8 of the 11 directors were present at meeting.
- ❑ 3 new members of the board were elected. Robert Bestow, Dr. Ching Piao TSAI and Teresa Salas- Campos
- ❑ No change were made on the Membership Subscriptions.
- ❑ Finally there were other businesses such as reports and financial statements.

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DAY 1

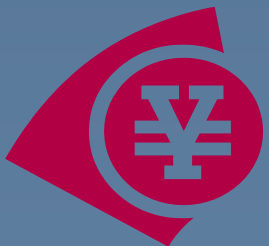
AGM – Formal Business





TREASURER'S REPORT

- o Income went down from last year at £54,024.
- o Expenditure went up from last year at £88,571. Deficit of £34,547 (last year it was surplus £3,736).
- o Reserves now stand at £108,822 Compared with £ 143,369 last year. In 2001 it was only £10,250
- o The Alliance is in a healthy financial position.





CHAIR'S REPORT

As presented in papers

- o Nothing added, no questions asked just approved unanimously



OTHER AGM FORMALITIES

- ❖ Resolution: 11 members of the Board of Directors. 1 from the host country, 1 chairman and 9 other members. Every year there should be 3 positions filled with new people.
- ❖ Approved appointment of, and welcomed, the new Board Members
- ❖ Approved Accounts and Re-elected the Auditors
- ❖ Annual Review of Membership Subscriptions Approved. No change was made.



International Alliance Strategic Review/Workshop

Carol Birks

- Introduced the steps and the finalization of the Strategic Review
- Goal, Vision, Mission , Values and Objectives were introduced
- The meeting was then divided into 4 groups who all presented their ideas:
 - To develop the operational structure required to achieve our objectives
 - To develop and enhance membership, partnerships and programs
 - To facilitate the exchange of information on ALS/MND care, education and research
 - To build a sustainable operating/funding model for the Alliance



Efforts and lessons of JALSA at the Earthquake, Tsunami and Nuclear Crisis in Japan

Yoshiaki Nagao //Yumiko Kawaguchi

Shared their experience after the Tohoku earthquake earlier this year.

- Action based approach
- Devastating effects
- Importance of Communication and making contact
- Gave us a Major Disaster Checklist
- Have done a magnificent job



Germany: Focusing on ALS/MND within a NMD Association

Antje Faatz

- Introduced the organisation
- Represented the work they have done over the past 2 years
- Joint Research Project
- Provide Education
- New Website www.als-selbsthilfe.de (als/mnd selfhelp)
- Internet community



Dream Deliveries for ALS Patients in Taiwan

Dr. Ching-Piao Tsai/Dr. Chi-Hsin Huang

- Shared 3 beautiful stories of how dreams come true
- Seeing Mt. Jade
- A Belated Wedding Party
- Su-lan's Journey Home

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X^o Brazilian Symposium on MND/ALS

Tatiana Mesquita e Silva

- Shared Arbela's activities throughout this year:
- 1st Meeting for Brazilian and Hispanic Associations for ALS
- 10th Brazilian Symposium on MND-ALS
- International ALS day – Soccer game in RIO



The Value of an Education Service

Robert Bestow

- Introduced the educational service MND Scotland provides and the importance of having that service
- Patient Information Folder – based on a model from ALS Canada
- Integrated Care Pathway
- Material for teenagers age 12-14

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An ALS Patient's Life with Cough Assist (mechanical insufflator-exsufflator)

Satomi Homma

- Explained Mr. Okabe experience with Cough Assist
- Emphasized the benefits of it
- Now the Cough Assist is covered by public medical insurance (April 2010)

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Then

Last night – the ‘Warm and Fuzzy’

We had great food, drinks and some time to
get to know each other a bit better

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DAY 2



Update on Turkish Partnership

Rachael Marsden

- Explained the partnerships history and all the work that has been done through that.
 - Education
 - Involving politician
 - Visits
 - Sharing information
 - ALS/MND more known
 - 7 Care Centers
- Now it 's running by itself!



Russia Estonia and Greece ALS/MND Outreach Initiative

Kathy Mitchell

- Explained her work done in Greece, Estonia and Athens
- Goals:
 - Political Advocacy
 - Public Awareness
 - Professional Education
 - Patient and Family Support
 - Sustainable resources
 - Capacity development
 - Global networking



ALS Hope Foundations partnership with Isr-ALS

Sara Feldman

- Told us about the partnership between these two organisations
- Visits – meetings with Social Workers and Palliative Care Doctor
- Communication Conference
- Tel Aviv – talking with Physical Therapist and Respiratory Therapist

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Presentation of the Finnish Neuromuscular Disorders Association

Eveliina Pollari

- Introduced the Association
- A lot of activities
 - Support, informing, meetings, volunteers
 - Training courses, communication, counselling



Incurable Optimism

Steve Bell

- We got news from the amazing Patrick and his journey of painting 100 portraits before ALS takes away his ability to do that and also got introduced to a new Incurable Optimist!
- Alistair Banks
- **www.alistairtheoptimist.org**
- www.patricktheoptimist.com

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MND Association of South Africa

Franclo Henning

- Introduced the association
- Challenges
 - to get consultants
 - No support from Government
 - Referral basis
 - Access to Patients



Strategic Review – Final Plan

Jeffrey Deitch

- Organisational - Jeff
- Membership – Jane
- Partnership – Teresa
- Program – Carol
- Funding – Evy
- Communication and PR strategy – Steve and Bob



International Alliance of ALS/MND Associations

19th Annual Meeting

SYDNEY



**We look forward to seeing
you all this time next year
at**





International Alliance of ALS/MND Associations



20th Annual Meeting



in

Chicago, USA

International Alliance of ALS/MND Associations



“Hope is Stronger than Fear”

(Nir Tsoran, IsrALS – Toronto 2007)

Let’s all be incurable optimists!