



**International Alliance of ALS/MND  
Associations  
18<sup>th</sup> Annual Meeting**

**JW Marriot – Grande Lakes**

**ORLANDO**

**December 2010**





## RECORD ATTENDANCE

- ◆ Record year again - 96 Delegates /Observers (Last Year -89 was a record)
- ◆ Representing at least 21 Member Associations and guest come from 23 countries
- ◆ Apart from floor questions, we received presentations / contributions from the Platform by representatives of the Associations of 12 different countries on their experiences, challenges and successes



# SUPPORT GRANT PANEL

## Wednesday Evening

Half -yearly meeting to Review Progress, to Consider New Applications and to Discuss the future of the Programme

- *No grant was awarded at this meeting.*
- *9 new grants have been awarded, amounting in total to £9,300.*
- *Since the inception of the programme exactly seven years ago, we have awarded total grants of £ 60,025*
- *Following which - current reserve now stand at £19,532.*



## BOARD OF DIRECTORS

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

- ❑ 9 of the 11 directors were present at meeting.
- ❑ 3 new members of the board were elected. Carol Birks, Sharon Matland and Evy Reviere.
- ❑ 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**

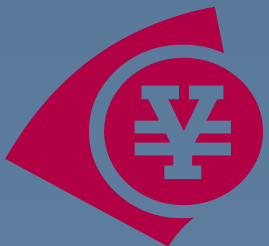
**AGM – Formal Business**





## TREASURER'S REPORT

- o Income went up from last year at £79,367.
- o Expenditure went up from last year at £75,631. Surplus of £3,736 (last year it was £1,262).
- o Reserves now stand at £143,369 Compared with £ 140,695 last year. In 2001 it was only £10,250
- o The Alliance is in a healthy financial position and it's position has been getting better.
- o Jeffery Deitch presented Andrew Fleeson's report. Andrew is stepping down and Jeffery is taking over his role.





## 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 of ALS/MND Associations



## International Alliance Strategic Review

### Alan Graham

- Graduate consultant group University of Hertfordshire
  - Did primary and secondary research
  - Presented interim report via video
  - The Board of Directors discussed the report and identified six key subjects
- Mission and vision statement
- Overall aims and objectives
- Marketing
- Awareness/communications/branding/PR/website/documentation and materials
- Fundraising
- Membership levels and fee structure
- Organizational structure and resourcing
- These key subjects will be posted on the website immediately following the meetings. Provide feedback, ideas, suggestions, thoughts, solutions for the way forward by the end of January so that these can be reviewed by the board at its March meeting.



## ALS Iran-Nederland foundation

### Golshid Al Eshaq

- Introduced their organisation
  - Much help was needed
  - Very little general knowledge about ALS
  - No services for ALS patients
  - But they have done a great job even though they just started and have very well defined goals.



## ALS Never Again

Nayady Alcazar/Orestes Rodriguez

- Introduced their organisation
- Similar problems that new organisations face
  - Lack of knowledge and awareness about the disease
- Celebrated the Global Day
- Have taken actions in order to get the attention of the Health Minister and the media.
- Invitation to have our meeting in South America in the future



## Introducing Research Motor Neurone

### Cathrerine Lynch

- New name for the Irish Neurone Disease Research Foundation that was established in 2007.
- Use the unique Irish genetic makeup
- Want to attract the brightest young researchers and increase awareness.
- Have a complete database of all MND cases in Ireland over the past 15 years and a DNA bank with over 1200 samples
- Patients passports
- Tractor Girls 2010 - fundraising



# The ALS Association Transformation

Jane H. Gilbert

- Introduced their transformation process
- How they grew their tree
- Three main branches
  - RESEARCH/CARE GIVING/ADVOCACY
- Use the money for the people with ALS, cut back operational cost
- Promise fund



# Networking: importance and results of cooperation

Christian Lunetta

- NEMO – product of cooperation
  - Neuromuscular Omniculture
- AriSLA – product of cooperation
  - Italian Agency for the Research on ALS
- By working together with other organisations they've reach great results – especially to push the government
- Saw a clip from the film “I am here” about Mario Melazzini's incurable will to live .
- NY marathon runner – Francesco Canali



## Tracking Survey – do we do what our members want or expect?

### Karen Pearce

- Gave us a very interesting overview of how the Motor Neurone Disease Association use a tracking survey to see if they meet their users expectations
- Told us about the methodology
  - Have both structured questions and free text
- Six key fundamental things that have not changed since 1995
- Now 75% of patients have heard of MND before they were diagnosed
- Advanced decision in refusing treatment



### Building a support system to ALS patients in Israel – Achievements and goals

#### Efrat Carmi

- They have established an umbrella of services
  - Communication – palliative care – hot line
- Focused on research at first but now research and care are 50/50
- Have a program for newly diagnosed patients
- Now they collaborate with other organisations in order to be able to do more for ALS patients
- This organisation has been working with ALS Hope foundation
- Awareness campaign where the 120 people who die of ALS each year were represented by mannequins in numbered T-shirts



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### 15 years - ALS Liga Belgium

#### Evvy Reviere

- Explained their organisation and it's journey through the last 15 years.
  - All kinds of programs, both international and national
    - Assistance device services, federal project in 2012, care center
- Use famous people as their ambassadors
- Fight as Lions - campaign



# The future of the Alliance

Discussion session with the Board of Directors about the strategic review



## ALS-TDI: A Non Profit Biotech - update

### Steve Perrin

- Introduced their fundraising strategy
- Young faces of ALS – awareness campaign
- Explained the challenges they face and the process of creating new drugs
- Introduced their ideas on how to speed up the process and reduce cost
- Emphazied the importance of working togheter
- New Era – Paradigm shift in the Alliance meeting



## Forbes Norris Research Center

### Dee Norris

- Gave us a great presentation with the highlight of a newly published book written by their staff member
- Respiratory Management of ALS: Amyotrophic Lateral Sclerosis
- It's purpose is to help clinical personell to understand better the non invasive ventilaton in ALS patients enough to use it efficiently.



## Incurable Optimism

### Steve Bell

- We got to know the amazing Patrick and his journey of painting 100 portraits before ALS takes away his ability to do that
- We were encouraged to participate and find our own incurable optimists
- [www.patricktheoptimist.com](http://www.patricktheoptimist.com)

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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



## Teaching touches the future!

### Kathy Mitchell

- Introduced the work in Malta, Cyprus, Israel and Belgium
- We got a very clear picture of how different conditions are for ALS patients around the world.
- Made us well aware of how much we can achieve by sharing information and helping each others





## The English/Turkish Partnership

### Rachael Marsden

- Introduced the work that has been done in Turkey for the last 3 years through the partnership
- Their aim is to raise awareness of MND
- Working on creating a Care Centre
- Now nurses from Turkey will visit England

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## Sharing the care experience of ALS/MND between the strait

Dr Ching Piao TSAI

- Told us about the cooperation between countries in Asia
  - Their own meeting of sharing where they created a support group for patients
- Went to the Expo 2010 in Shanghai China.



## A positive life

### Mr. Yoshiyuki Fujisawa

- Told us about the life with ALS in Japan
- The journey of changing his home and learning how to live with ALS
- Explained the system in Japan and local support organisations
- We got to know him, his hobbies and intrests
- Hawaii trip and challenges
- The need to be global and the need for money



# Paulo Contijo Award in Medicine for research in the cause and treatment of ALS

Marcela Contijo and Taliana Silva

- Show what they are doing in Brazil regarding research
- Represented the PG Award 2010
- From 2011 the award will be given annually
- The best research will be rewarded with 20.000 US dollars
- Todos Por ELA
  - Digital journal specially made from patients
- Introduction of ABRELA

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# RNA is now in the Spotlight

**Jeffrey S. Deitch**

- Explained to us in human terms the complex concept of RNA and it's quiet revolution



# International Alliance of ALS/MND Associations

## 18<sup>th</sup> Annual Meeting

### ORLANDO



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





# International Alliance of ALS/MND Associations



19<sup>th</sup> Annual Meeting

in



Sidney, AUSTRALIA



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*“Hope is Stronger than Fear”*

*( Nir Tsoran, IsrALS – Toronto 2007)*

*Let’s all be incurable optimists!*