

**International Alliance of ALS/MND
Associations
17th Annual Meeting**

Maritim Hotel

BERLIN

December 2009





RECORD ATTENDANCE

- ◆ 89 Delegates /Observers (Last Year –63)
- ◆ Representing at least 21 Member Associations and guest come from 22 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

- *One new Grant was awarded at this meeting.*
- *10 new grants have been awarded, amounting in total to £11,500.*
- *Since the inception of the programme exactly six years ago, we have awarded total grants of £44,100*
- *Following which - current reserve now stand at £8,800.*



BOARD OF DIRECTORS

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

- All the 11 directors were present at meeting.
- 2 new members of the board were elected. Jens Spanfelt and Ales Praznikar
- 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

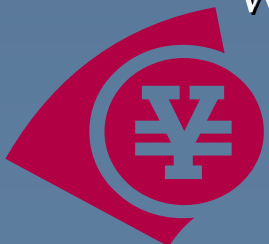
AGM – Formal Business





TREASURER'S REPORT

- o Income went up from last year at £69,867.
- o Expenditure went a bit up from last year at £68,605. Surplus of £1,262 (against last year deficit of £2,765).
- o Reserves now stand at £140,695. Compared with £138,371 last year. In 2001 it was only £10,250
- o Even if the global economic did affect the Alliance the Alliance is in a healthy financial position.
- o Andrew Fleeson presented his report for the last time as a Honorary Treasurer and we thank him for his wonderful work throughout the years.





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.

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From Bench to bedside pals: AISLA mission and goal in 2009

Mario Melazzini and Monica Cattani

- Started the activities of AriSLA – the agency for research on ALS
 - Launched it's first call for ideas
 - 4 research areas
 - Evaluation is based on quality, transparency, equal treatment, impartiality, efficiency and rapidity.
 - Activities will start April 2010
- The emphasis is also on the importance of taking good care of everyone until the cure has been found.
- Nemo is an care centre for all patients with neurological diseases but the most of the patients have ALS
- Fundraising is difficult but the strength of the organisation is it's patients
- SLA- Start Living Again!



The Les Turner ALS Patient Service program

Judy Richman

- Introduced their Home Care team
 - Consists of 3 nurses and 1 social worker
 - They provide consult and education
 - Ongoing disease education
 - coordinate care plans
 - provide support and guidance throughout the course of the disease
- This service is provided in the patients home
- It ´s free service for the patient and his family!



The right to live

Birger Bergmann Jeppesen

- Explained how a person that can only move his or her eyes can live a fulfilling and meaningful life.
- We saw a film about having the choice of a ventilator and how it is possible to be in charge of you own life even if you are paralysed

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Muscular Dystrophy Association ALS division

Annie Kennedy

- Gave us an overview of the great work they have done.
- More than 250 million dollar research program
 - More than 350 research programs for ALS
- ALS clinical research network
- Researchers everywhere in the world can apply



4000 Screams

Alberto García Redondo

- Introduced the work and goals of FUNDELA
 - Research, information and raising awareness
- We saw the video 4000 Screams by Ignacio Delgado Beltrami and got to know how it has raised awareness in Spain and other impact it has had

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Working together in Australia 2009

Carol Birks

- Told us about the great work that has been done by MND Australia the year 2009.
 - Used the video from Israel
 - Research
 - Cooperation with other organizations in Australia
- We saw a 10 minute clip from the film “A glass half full: living with MND” where the positive life of an ALS patient is introduced



Recruitment of a public relations firm and production of an ALS public service announcement

David Cameron

- Gave us a very interesting overview of how ALS Society of Canada has used the media to reach their goal of educating and fundraising.
 - The cooperation with a public relation firm
 - Head and Shoulders
 - TV, Radio and in print
 - Also “I love you” in the radio

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Nir Tsoran – a colleague and a leader Out of the box – raising awareness with fun

Efrat Carmi

- April this year we lost Nir Tsoran a positive fighter who did an amazing job in Israel both in raising awareness and raising funds for research.
- “The red paper clip”
 - Trading something that cost nothing for something a bit more valuable
 - From 0 – 50.000 \$!
- “Walk the land for those who can’t”
 - 36.000 \$ goal and they’re almost there



MND Scotland 2009

Rebranding

- The need for simple and new name explained
 - Use of international sign for hope

The work done by MND Scotland 2009

- Explained the great job that the organization does in Scotland
 - Pay for care team, loan service for equipment, counselling service, volunteer development, library and information service, working together with the government and other organizations.



Independent living – from my own experiences

Evald Krog

- Gave us an insight in his independent life with a ventilator and how he is able to control his life completely and how the Danish welfare system makes it possible for him to be a part of the society and to contribute to the society instead of being a burden.
- Talked about the VIVE project in Iceland, active and welfare that is a whole new approach to the welfare system and how they are getting people out of the institutions and back into the society again.



The ALS Association Year in Review

Jane Gilbert

- Told us about the great work that was done this year
 - Research, patient care, raising public awareness and a lot more
- Walk to defeat ALS introduced
- We saw a video about a care system similar to share the care. This care system is called Care Connection and was very interesting and showed how friends, coworkers and other can help and really make a difference in both the patient's life and the life of the patient's family.

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ALS/TDI: A Comprehensive Approach to Therapeutic Development for Today's ALS patients

Steve Perrin

- Introduced the ALS/TDI a non profit biotech
- Explained the reasearch process and gave us an insight in how much work there has been done and still needs to be done.
- Talked about the patient forum they have established
- Emphazied the importance of working togheter



Eye to Eye communication

Birger Bergmann Jeppesen

- Showed us the film “speaking with the eyes”
 - It demonstrates how Birger, who can only move his eyes can communicate in an effective way and have all kinds of conversations only by using a lettersystem that was introduced in the film aswell.



Report on the “international symposium” and Research on Home Care of Patients with ALS in East Asia

Yumiko Kawaguchi

- Gave us an introduction on the Home Care of patients
- Showed us the film “Mr. Koutani’s house”
 - His friends helped him to get out of the hospital and into his own home where he can live an independent life and is able to dance even though he is in a wheelchair and needs a lot of care.
 - He is able to live independently and is not a burden on his family

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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



Big Picture – Small Word – an update of the Eastern European Initiative

Kathy Mitchell

- Introduced the work in Serbia, Croatia, and Slovenia
- What they are doing now and what their goals are
- The Canada Fund Grant introduced
- Passion persistence and patience



A return visit to Turkey

Rachael Marsden/Jan Clarke

- Introduced the work that was done in Turkey when they revisited
- Meeting nurses that they trained last year
- Meeting friends and families
- Talked about Care Centre
- Going there again to teach

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See the life of ALS in Taiwan

Dr Ching Piao TSAI

- Introduced their really good work in Taiwan
 - Physical care, information, home care, computer aid, group therapy and more
- Introduced this event that had the purpose of recognizing the meaning and value of people who live with ALS
- People from other parts in Asia, everyone shared their experiences in enhancing the quality of life of ALS patients and families



MND Year of Care Pathway: A model for others?

Heidi Macleod

- Lists the full range of interventions over the course of a year in “commissioning currency”.
- Explained how commissioners, health and social care professionals use the pathway
- User friendly and lists cost for each aspect of care and equipment.
- Affordable – deliverable- acceptable

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

Marcela Contijo and Francisco Rotta

- Show what they are doing in Brazil regarding research
- Represented the PG Award 2009
- From 2012 the award will be given annually



How to answer the question: “Is there any progress in finding a cure?”

Jeffrey S. Deitch

- Told us about a article called “costly error in health research”
- Three things:
 - Don’t get caught up in the scientific debate
 - Don’t accept the “technological fix”
 - After this therefore because of this
- Explained where we are at in research



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



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18th Annual Meeting

in

Orlando, FLORIDA



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“Hope is Stronger than Fear”

(Nir Tsoran, IsrALS – Toronto 2007)