International Alliance of ALS/MND Associations
18th Annual Meeting
Wednesday 8 December – 9.15
Mediterranean 6/7 JW Marriott - Grande Lakes, Orlando, USA

9.15	1	Welcome and Introduction		
9.30	2	International Alliance Strategic Review	Alan Graham	
10.00	3.	Iran - Nederland	Iran - Nederland	Page 2
10.20	4	ALS Never Again	Nayady Alcazar/ Orestes Rodriguez	Page 3
10.40	*Morning Refreshments*			
11.10	5	Introducing Research Motor Neurone	Catherine Lynch	Page 4
11. 30	6	The ALS Association Transformation	Jane H. Gilbert	Page 5
11.50	7	AISLA	Monica Cattani	Page 6
12.10	8	The Motor Neurone Disease Association Tracking Survey – do we do what our members want or expect?	Karen Pearce	Page 7
12.30	*Lunch*			
13.30	9	Building a Support System to ALS Patients in Israel – Achievements and Goals	Efrat Carmi	Page 8
13.50	10	15 Years – ALS Liga Belgium	Evy Reviers	Page 9
14.15	11	Strategic Review – open discussion	Board of Directors	Page 10
15.00		*Afternoon Refreshments*		
15.30	12	Strategic Review – open discussion -Summary	Board of Directors	
16.00	13	ALS-TDI update	Steve Perrin	Page 11
16.20	14	Forbes Norris Research Center	Dee Norris	Page 12
16.40	15	Motor Neurone (MND) Association's Awareness Campaign, Incurable Optimism	Steve Bell	Page 13

International Alliance of ALS/MND Associations

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: **Iran - Nederland**

TITLE OF PRESENTATION: **Iran - Nederland**

ABSTRACT: Unavailable

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKERS: **Nayady Alcazar/**
Orestes Rodriguez

TITLE OF PRESENTATION: "ALS Never Again"

ABSTRACT:

Our presentation will be made in six parts, which describe the formation of our association, actions implemented, the need for international support and proposals for South America.

The points are:

1. How and why it was founded ELA Peru
2. Lack of information and knowledge of the disease in Peru
3. Actions taken before the Health Department and media
4. Failure of medical equipment, on the alliance's member associations
5. Need of International support, by the Alliance's member associations.
6. Proposal to organize the meeting in South America

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Catherine Lynch

TITLE OF PRESENTATION: Introducing Research Motor Neurone

ABSTRACT:

On Nov 27th 2007 The Irish Motor Neurone Disease Research Foundation (IMNDRF) was established to support the research carried out by the Irish MND research group. IMNDRF is currently trading as Research Motor Neurone (RMN).

The unique genetic makeup of the Irish population presents both a feasible and highly desirable cohort for population – based studies. The Irish MND research team have a complete database of all MND cases in Ireland over the past 15 years, and during this time they have undertaken extensive mapping and characterization of the disease.

RMN aims to maximize recourses by supporting all activities carried out by the team. They also aim to increase awareness of the condition while fostering and supporting all fundraising initiatives.

International Alliance of ALS/MND Associations

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: **Jane H. Gilbert**
President and CEO
The ALS Association

TITLE OF PRESENTATION: **The ALS Association Transformation**

ABSTRACT:

The Association, as a well-established and large member of the ALS community with a fine track record of growth, development of services, programs and outreach in a very diverse marketplace, is evolving and restructuring to deal with the challenges of the current climate and to meet those of the future. There are similar issues that many organizations are facing—whether large or small, young or not so young.

The Association's transformation began four years ago with a Booz Allen Hamilton management assessment of several organizational areas including: governance; fundraising; communications and technology. It became apparent through this process, that we needed to recreate ourselves—to develop a new business model to more effectively meet the current and future needs of people with ALS, their families and caregivers.

This presentation provides an overview of some of the accomplishments to-date: moving the national office to Washington D.C.; integrating our chapters' senior leadership into the governance structure; developing a national fundraising and development program; expanding and enhancing our communications outreach; and improving technology.

As a 25 year old organization, The Association's transformation will continue as we strive to meet the needs of people with ALS, their families and caregivers.

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: **Monica Cattani, Christian Lunetta, Mario Melazzini**

TITLE OF PRESENTATION: **Networking: importance and results of cooperation**

ABSTRACT:

During last years Aisla has done an intensive activity of development for Italian Pals, both about research and care and during last meetings we have shared our experience with all other Associations members of the Alliance.

We have realized that concrete cooperation with other realities operating in our country is a great and really powerful instrument: Centro Clinico Nemo and Arisla, the Italian Agency for the Research on Als are the concrete result but represent also an important starting point.

This attitude toward networking has brought us to push Italian Government, in particular Italian Minister of Health, to establish a technical very operative group, sharing experiences and needs of all actors (patient associations, physicians, institutional representatives etc) involved in neuromuscular diseases with similar difficult path of diagnosis and care, in order to guarantee a final document with a sort of Guide Lines to be applied by everybody and to guarantee all legislative supports equally in all regions in Italy without any kind of disparity of treatment.

International Alliance of ALS/MND Associations

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Karen Pearce

TITLE OF PRESENTATION: The Motor Neurone Disease Association Tracking Survey – do we do what our members want or expect?

ABSTRACT:

It is essential that the Motor Neurone Disease Association evaluates its services to people with MND to enable us to focus funding and services on the issues that are most important to those affected by MND. We also need to monitor changes in the delivery of statutory care which may necessitate action by the Association.

Two “Tracking Surveys” containing a range of questions have been undertaken in the last 5 years. The 2010 questionnaires were sent to members of the Association who agreed to take part and consisted of 32 questions. 43% replied, equating to about 15% of all people in touch with the Association at that time. Analysis of the sample’s demography was consistent with published MND populations.

The results indicated that the Association is doing what people with MND want, namely supporting research, care and education of professionals. It showed that the satisfaction of the Associations main services is high, and that there has been a dramatic increase in demand for them. Respondents regarded early diagnosis, care centres’ and professionals’ knowledge as the three most important issues about the disease.

Compared with 2005 the referral time from GP to neurologist remains the same but once the referral is received they see the neurologist more quickly. This is likely to be due to National Health Service (NHS) waiting list initiatives and proposed abolition to these may be reflected in the next survey. Otherwise satisfaction levels were the same or better compared with 2005.

The survey raised important points concerning attitudes to end of life issues, such as place of death and advanced directives; 25% of respondents wanted to talk about these but did not get the opportunity but 50% did not wish to discuss these issues at all, indicating a need for both the Association and practitioners to handle these issues very sensitively.

The Association, as a result of the survey, is linking with the National Institute for Health and Clinical Excellence (NICE) to support the development of end of life standards. In addition it is working with the Royal College of General Practitioners to increase GP awareness and knowledge through the proposed appointment of a clinical lead in MND as well as working with the Department of Health on a wheelchair delivery model.

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Efrat Carmi, IsrA.L.S, CEO

TITLE OF PRESENTATION: Building a support system to ALS patients in Israel- Achievements and goals.

ABSTRACT:

In 2008, in response to a great need and call from ALS patients and their family members, IsrA.L.S has established a Patient Care and Support Department.
The first goal of the department was to create an umbrella of sponsored services that patients couldn't get from the state. The main and most significant one is the communication service with a clear mission that no ALS patient will stay unheard. Another goal was to ease patients' way in the bureaucratic maze by publishing a special guide to the rights and benefits of ALS patients in Israel. Patients support groups and forums, family booklets, quarterly magazine, workshops for professional teams and fighting for better rights and benefits for ALS patients, are only few of the achievements of the department.
We are going into 2011 with a wish to expand our services and a goal to reach closed population sectors that do not consume clinical and para clinical services and are not aware of the alternatives that can better ALS patients' quality of life.

:

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Evy Reviers

TITLE OF PRESENTATION: 15 Years – ALS Liga Belgium

ABSTRACT:

The presentation tells about what we have done, what we have achieved and what we want to do in the future.

18th ANNUAL MEETING

SPEAKERS: Carol Birks, Rodney Harris

TITLE OF PRESENTATION: **Talking up ALS/MND**

ABSTRACT:

Carol Birks and Rodney Harris kindly gave up their time in the schedule for Talking up ALS/MND to create time for an open discussion about the Strategic Review. The Board of Directors were in control of the discussions and each table had one of these following themes:

A. ***Mission, Vision, Aims and Objectives, Governance, Organisational Structure, Constitution (Sharon, Alan)***

B. ***Membership Levels, Fee Structure, Identification of New Members and New Countries, Mentoring***
(Ales, Carol, Yumiko)

C. ***Awareness / Communications / Branding / PR / Website / Documentation /Literature / Resource Library***
(Monica, Gudjon, Evy)

D. ***Fundraising, Grants, Bursaries, Financial Support***
(Jeff, Steve)

E. ***Programmes – Partnerships, Knowledge Transfer, Exchange Visits***
(Jens, Francisco)

.

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Steve Perrin, Ph.D.

TITLE OF PRESENTATION: A New Era of Drug Development for ALS

ABSTRACT:

The ALS Therapy Development Institute is a non-profit biotech devoted to discovery and development of effective treatments for ALS. As such, the Institute operates a state-of-the-art research facility in Cambridge, Massachusetts. ALS TDI has assembled a team of 25 drug development experts who work towards a better understanding of the cellular and molecular mechanisms leading to disease onset and progression. ALS TDI executes upwards of 30 preclinical drug development programs annually based on these molecular mechanisms.

ALS TDI believes that the pharma-biotech industry is on the verge of entering a new era of drug development. I will present models on how non profit institutes can fit into the drug development process to develop effective treatments for patients. I will review the preclinical drug development process that ALS TDI has implemented focusing on recent developments and up coming programs for 2011. I will review ALS TDI's internal Knowledge Management System and how it enables scientists to identify promising therapeutic targets and track existing programs.

International Alliance of ALS/MND Associations

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Dee Norris

TITLE OF PRESENTATION: Forbes Norris Center

ABSTRACT: Unavailable

18th ANNUAL MEETING
JW MARRIOTT – GRANDE LAKES, ORLANDO
8 & 9 December 2010

SPEAKER: Steve Bell

TITLE OF PRESENTATION: Motor Neurone Disease (MND) Association's awareness campaign, Incurable Optimism

ABSTRACT

This year the MND Association launched its new awareness campaign, Incurable Optimism. The campaign took a very different approach to previous campaigns. Rather than solely focusing on the cruel nature of MND we decided to highlight the amazing and positive spirit of the MND Association community and how it is this spirit that keeps us fighting the disease.

MND is incurable, but so is our optimism. It is our incurable optimism that one day we will beat this disease that drives people to raise and donate money to help fund research to lead to future treatments. It is incurable optimism that keeps our researchers and scientists in the lab, piecing together the picture of MND. It is incurable optimism that drives our volunteers to work so passionately each and every day. It is optimism that drives us to achieve a world free of MND.

We spread our message of incurable optimism by working closely with father of three Patrick Joyce who was diagnosed with MND in 2008. Patrick came up with the idea of painting the portraits of 100 incurable optimists to show that behind the horrible statistics there are people fighting to stop this disease, people giving up their lives to care for people living with it, with dignity, fortitude and a sense of humour. Through Patrick's portraits we wanted to show that these are real people, each with an amazing story of courage and hope for the future. We wanted to tell their stories and through the telling, inspire more people to help us.

The presentation will look at how we came up with this concept and worked closely with Patrick to secure media coverage and advertising space to get our message out. It will also outline the next steps of the campaign and explore the possibility of creating an international movement of incurable optimism.