

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

9.00	16	Cyprus and Malta	Kathy Mitchell	page 2
9.20	17	A return visit to Turkey	Rachael Marsden	page 3
9.40	18	China, Japan and Taiwan	Dr Ching Piao Tsai	page 4
10.00	19	Fundraising and America	Mr Fujisawa	page 5
10.20		<i>Morning Refreshments</i>		
10.50		Group Photograph		
11.10	20	IPG	Marcella Gontijo	page 6
11.30	21	Research	Jeffrey Deitch	page 8
12.00	22	Sydney	Carol Birks	
12.15	23	Meeting Summary	Arny Gudjonsdottir	
12.30		<i>Lunch</i>		
14.00		Ask the Experts The programme includes:		
		Solving One of History's Great Mysteries: Why Are So Few Patients Enrolling in ALS Research Studies? - Richard S. Bedlack MD PhD FAAN		
		ALS Therapeutics in 2010 - Merit Cudkowicz MD		
		Human Neural Stem Cell Transplantation for the Treatment of ALS - Nicholas Boulis MD		
		Genetics of ALS – what's new and what's next? - Rosa Rademakers PhD.		

This event has been kindly sponsored by:
ALS Hope Foundation





International Alliance of ALS/MND Associations

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

SPEAKER: Kathy Mitchell
Professor Faculty of Nursing
University of Ottawa
Algonquin College
Ottawa Ontario, Canada

TITLE OF PRESENTATION: Teaching Touches the Future! Improving care by professional education, political advocacy and public awareness

ABSTRACT:

Building on previous successes this presentation will highlight the ongoing education outreach programs in Europe to assist organizations to increase knowledge of the current progress in ALS/MND care.

A visit to the Malta Hospice group, the Cyprus Institute of Neurology, the Israel ALS Association and the Belgium ALS Liga will be briefly presented.

By sharing expertise and a willingness to collaborate I support the goals of the International Alliance to create sustainable resources and ongoing partnerships to improve quality of life for ALS/MND patients and their families.

The potential for other countries to create linkages will be explored.

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SPEAKER: Rachael Marsden

TITLE OF PRESENTATION: The English / Turkish Partnership

ABSTRACT:

For the last 3 years the International Alliance of ALS/MND has supported two Care Centre Coordinators from England to work with Professor Coskun Ozdemir from the Association Neuromuscular Disorders of Turkey.

The aim has been to raise awareness of MND. To teach nurses how to care for patients in a timely and proactive way. And to try to establish a care structure for patients living with MND in Istanbul

This talk will discuss the positive outcomes from this close Alliance. It will demonstrate that over the last 3 years how attitudes have changed and the progress that has been made.

Following the last visit it was felt that the nurses are empowered to establish their own care centre in Istanbul, for this they have the support of the Principle of the University of Istanbul. They are meeting to discuss how this may be made possible within their own care structure

Many of the nurses who attended the course will be visiting care centres in Oxford and London in the New Year to observe the Multidisciplinary approach to care to MND and how each patient are reviewed regularly and how care is planned.

We are very grateful to the support of the International Alliance of ALS/MND Association who have made this work possible.



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SPEAKER:

Dr Ching Piao TSAI
Taiwan MNDA

TITLE OF PRESENTATION: Sharing the care experience of ALS/MND between the strait

ABSTRACT:

Taiwan MNDA funded in 1997, however, there is no official ALS/MND organization for China so far, only an informal ALS/MND patient supporting group organized by 5 major hospital in Beijing, Shanghai and Kwangju. Although the political relationship between the strait is still strict, however, cooperation between medical and economical affairs became more and more intimately.

Taiwan MNDA began the ALS/MND multidiscipline care earlier including special respiratory care unit, home care as well as hospice in which China has not yet been started. In 20 June 2010, there was a joint academic meeting in Beijing discussing the main topic for ALS/MND multidiscipline care, treatment and genetic studies for Drs and care giver to sharing their experience.

In 21 June 2010, for simultaneously celebration the ALS/MND global day, patients and their care-giver from Taiwan and China gathered together to attend the Expo 2010 Shanghai China, they shared the experience in the communication method including eye tracking computer, communication board and psychological support as well. The interaction between the strait showed that there were no boundaries in the worldwide fight against ALS/MND.



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SPEAKER: Mr. Yoshiyuki Fujisawa

TITLE OF PRESENTATION: A Positive Life

ABSTRACT:

In his presentation Mr. Fujisawa will describe his own experience as an ALS patient. He will talk about his decision to live as long as possible and the various ways in which he has drawn on the resources of the state and help from people around him to improve his quality of life and prepare for the future as his illness progresses. This will include a description of the modifications he made to his house as well as some of the difficulties he has encountered in communicating and how he has worked to overcome them. He will share his thoughts and personal experiences regarding the ways in which by coming together and sharing their experiences fellow ALS patients and their families and caregivers can provide each other with valuable knowledge and support. He will also discuss the idea of “global standards” and why he feels that it is important that patients with ALS make their own choices based on what he calls their “personal culture” without being pressured to take a certain approach by external norms or standards. Mr. Fujisawa's background is in finance, and he will draw analogies to the pros and cons of “globalization” and “global standards” that have arisen in that field in his discussion of the potential risks and benefits of “globalized” standards when it comes to ALS. In closing Mr. Fujisawa will briefly mention some new research utilizing iPS cells.

About Mr. Fujisawa:

**1961 Graduated from the University of Tokyo.
Joined The Industrial Bank of Japan Ltd. (IBJ).**

2000 Became Chairman.

**2002 Became Chairman of Merrill Lynch Japan Securities Ltd. following integration with
MIZUHO Financial Group.**

2007 Retired.



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SPEAKER: Marcela Gontijo

TITLE OF PRESENTATION: Promotion of the International Medicine PG Award for researches in the cause and treatment of ALS and presentation of the Project TODOS POR ELA, a Brazilian digital journal specially made for ALS patients.

ABSTRACT:

PG Award

The PG Award is open to researchers, students and professionals from medicine papers, the latter related to the cause and cure of ALS. The first PG Award was given in 2007 to the Brazilian researcher Agnes Lumi Nishimura from studies at King's College London – Institute of Psychiatry. In 2009, the number of registration increased in 400% when compared to the first edition in number of applicants. The second PG Award was given to the Belgian researcher Peter Carmeliet from University of Leuven (Belgium.)

Along with MND Association and an international judging committee the next PG Award opens its inscriptions from the next 21th International Symposium ALS/MND Orlando and is scheduled for delivery ceremony in 2011 at 22th International Symposium ALS/MND. The PG Award consist of a monetary value US\$20.000,00 (twenty thousand US dollars) and a gold medal. The regulation will be available from november at website www.ipg.org.br

PG Award

PG Award is open to researchers, students and professionals working in the Medicine area, studying the causes and treatment of ALS. The first PG Award was given in 2007 to the Brazilian researcher Agnes Lumi Nishimura for her studies at King's College in London, in the Institute of Psychiatry.

In 2009, the number of registrations increased in 400% when compared to the first edition in number of applicants. The second PG Award was given to the Belgian researcher Peter Carmeliet from University of Leuven in Belgium.

Along with MND Association and an international judging committee, the next PG Award opens its registrations in Orlando, during the 21st International ALS/MND Symposium. The award will be delivered in a ceremony scheduled for the 22nd International ALS/MND Symposium in 2011. The PG Award consists of a monetary value of US\$ 20,000 (twenty thousand US dollars) and a gold medal. Regulations will be available from November on at www.ipg.org.br.

TODOS POR ELA

Todos por Ela site is a digital journal specially made for patients suffering with Amyotrophic Lateral Sclerosis (ALS), their caregivers and professionals who deal with the disease.

The idea of **Todos por Ela** came up when the team working at Instituto Paulo Gontijo realized it was necessary some communication in the media to talk specifically about Amyotrophic Lateral Sclerosis to patients, caregivers, doctors and experts from different health areas. The experience of five years working and encouraging scientific research mainly on the motor neuron disease, showed how important it was to help and provide information on everything related to the disease to patients and their caregivers.

With ALS researches and the Medicine PG Award, it became very clear that information on this disease should be organized all together in just one place. The proposal was presented to professionals in the area and, with full support of the scientific community, **Todos por Ela** started to be organized, aiming at informing on scientific breakthroughs, technologies, accessibility, general information on ALS and how to live with the disease.

In addition to this, the project made it possible to create a data bank with information about places which attend ALS patients that may be easily and constantly updated.

Adriana Klein, an occupational therapist and applicant to the 1st Medicine PG Award with the theses MIBRELA – Brazilian Interactive Manual on Amyotrophic Lateral Sclerosis – provides relevant information in the site besides giving orientations to facilitate the daily life of ALS patients.



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SPEAKER: Jeffrey S. Deitch, PhD

Assistant Professor, Dept. of Neurology, Drexel University College of Medicine
Managing Director, ALS Hope Foundation, Philadelphia, PA

TITLE OF PRESENTATION: RNA is now in the Spotlight

ABSTRACT: Molecules of DNA (Deoxy-riboNucleic Acid) carry the genetic blueprint for creating each living being. Segments of DNA, called genes, are like sentences, describing a particular cellular protein in detail. The first step in “reading” a DNA sentence is to transcribe it into a molecule of messenger RNA (RiboNucleic Acid). This mRNA sentence is trimmed of unnecessary words, and even whole phrases might be clipped out, by editing enzymes in the nucleus. Eventually the modified mRNA is transported into the cytoplasm of the cell. There, a different type of RNA molecule, called transfer RNA, helps translate the mRNA into a sequence of amino acids, which forms the protein described by the DNA.

This simple view of RNA has become far more complex (of course!) in the last decade. There are hundreds of enzymes in the nucleus that edit the mRNA, and they can greatly alter how the DNA “sentence” is translated into mRNA. In addition, there are small bits of other types of RNA molecules floating around the nucleus and cytoplasm. Their job is not to be the intermediary translator between DNA and protein. Rather, they bind to and modify the mRNA, adding another layer of control over what proteins get made, in what quantity, and how quickly.

The biopharmaceutical industry is abuzz with attempts to harness the power of these active bits of RNA and use them as therapeutics to enhance or suppress expression of proteins in a particular disease pathway. In addition, recently discovered proteins that appear to be involved in neurodegeneration and can cause ALS when mutated (e.g., TDP43, FUS), are normally involved in regulation of RNA. This is prompting us to question just what role RNA processing plays in motor neuron disease, and does it provide an opportunity for intervention in disease onset and progression?

This presentation will give an overview of the terms, mechanisms and jargon surrounding RNA.