

Report on the 18th Annual Meeting of the International Alliance of ALS/MND Associations, Allied Professionals Forum and 21st International Symposium on ALS/MND



David Ali, Vice President MND Australia, and Carol Birks, National Executive Director, attended the 18th meeting of the International Alliance of ALS/MND Associations in Orlando, Florida on 8 and 9 December as the MND Australia delegates. 30 member Associations from 23 countries were represented by a record number of 96 delegates and observers.

This year's meetings were very interactive with the room set up with round tables and no name tags to encourage people to make new acquaintances and to share ideas. As usual the March of Faces

banners flanked the room and once again this year an Australian person with MND, Mr Peter Ruddock from Victoria, was included on the latest International March of Faces Banner.

The AGM

The meetings commenced at 8.30am on the 8th December with the AGM chaired by the President Gudjon Sigurdsson from Iceland, ably assisted by Alliance Coordinator Donna Corbett and Gudjon's daughter Arny (pictured right). At the meeting three new Alliance board members were elected; Sharon Matland ALSA, Evy Reviere ALS Liga (Belgium) and Carol Birks MND Australia. Andrew Fleeson stepped down as Honourary Treasurer and Jeff Deitch from ALS Hope took on the role. Jeff reported that the Alliance is currently in a good financial position with \$230,000 in reserves.



Initial Report on the Strategic Review of Alliance

The general meeting followed the AGM starting off with a presentation of findings from a recent strategic review commissioned by the Alliance. Alan Graham, board member of the Alliance, gave the presentation. The Business School at the University of Hertfordshire was engaged to carry out a review of the Alliance and has interviewed about 20 members via the phone and another 30 via the internet. The results showed that almost 90% of responders felt that the Alliance is achieving its objectives.

The review has confirmed the need to extend and promote existing programs such as the partnership program and to look at developing new programs. Feedback from the interviews provided the board with confirmation of member support for the employment of a CEO or Executive Director and with proposed themes for further discussion and review. Themes included:

- 1) mission and vision



- 2) aims and objectives
- 3) marketing/communications
- 4) fundraising
- 5) membership levels
- 6) organizational structure

Alan confirmed that the board aim to communicate a draft Strategic Plan to members prior to the next AGM. The board will also encourage members to work with the board to develop specific areas.

Following the presentation there was a suggestion by Dee Norris, Forbes Norris Research Center, that the board should be available to the entire Alliance to receive questions and further comments. Alliance members agreed with Dee and the day's program was subsequently reorganized to allow an interactive workshop on the Strategic review in place of the scheduled 'Talking up MND' workshop.

New Members

The rest of the day included 10 presentations from eight different countries. There was an introduction to two new members Stitching ALS Iran – Netherlands (SAIN) and ELA Peru. Another new member the Colombian ALS Association was due to present but unfortunately did not receive their visa in time.

Netherlands – Iran

Golshid Al Eshaq from the Netherlands, who recently lost her father to ALS, reported on their new organization established to support people living with MND in Iran. They have created a website in Farsi and set up a foundation aimed at providing financial and other support to people diagnosed with ALS living in Iran where her father was born. During her talk she explained how the group, Stitching ALS Iran – Netherland (SAIN), has started to conduct fundraising drives in order to support to people living in Iran. The website www.alsiran.com will be useful for Farsi speaking Australians who are living with MND.

Peru

The delegate from Peru provided an overview of this recently formed association which has a primary goal to educate the population about MND. There is still a lot of misinformation about MND in Peru with many people in remote areas of the country believing that the disease is the result of witchcraft. They have already established national lobbying activities and they have also started to collect equipment to loan to people living with MND throughout the country. ELA Peru's website: www.elaperu.org

Member updates

Ireland

Research Motor Neurone (RMN) reported on the unique genetic makeup of the Irish population. The Irish MND research team has 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 resources by supporting all activities carried out by the team. One of the other items they mentioned was a unique fundraising/awareness campaign called "Tractor Girls 2010" see: www.tg2010.com
RMN website- www.mnd.ie

USA

ALSA is 25 years old and Jane Gilbert, CEO, reported on its recent transformation. 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 they needed to recreate themselves and to develop a new business model to more effectively meet the current and future needs of people with ALS, their families and caregivers. To date they have

moved the national office to Washington D.C.; integrated their chapters' senior leadership into the governance structure; developed a national fundraising and development program; expanded and enhanced communications outreach; improved technology; reduced the national staff from 50 to 35 and cut their operating budget by around \$2 million whilst increasing funding and support to ALS care centres and chapters. Their focus is research, care giving and advocacy – www.alsa.org

Italy

The Italian association, Aisla, reported on achievements through partnerships with other neuromuscular groups leading to greater government recognition. They have had intensive activity over the last 12 months with increased networking highlighting the importance of cooperation in developing Neuromuscular Disease Care and Research centers in consultation with the Italian Ministry of Health.

AISLA has developed working groups to look at specific tasks:

1. Diagnosis – development of guidelines
2. Networks and Models of Care
3. Research
 - a. Clinical trials
 - b. Disease registry
4. Rehabilitation
5. Integrated care pathways



The group showed a motivational video featuring Professor Mario Melazzini, (pictured), who is the head of AISLA, on living a positive life and choosing to be a leader in the ALS community in Italy.

They also introduced us to a young person living with MND from Italy who with the help of two supporters had participated in the recent NYC Marathon - www.aisla.it

England, Wales and Northern Ireland

Karen Pearce from MND reported on their 2010 'tracking survey'. The results indicated that the Association is doing what people with MND want, namely supporting research, providing care and support and educating health 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, MND care centres' (clinics) 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) targets of 4 to 6 weeks from receipt of referral. The survey confirmed that 34% of members had not been told about the association at diagnosis but that 75% had heard of the



Association. 25% were not linked to a MND care centre and were not receiving coordinated care.

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 were not given the opportunity. However, 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.

Key action areas as a result of the survey include:

1. End of Life Care - linking with the National Institute for Health and Clinical Excellence (NICE) to support the development of end of life standards
2. Awareness - working with the Royal College of General Practitioners to increase GP awareness and knowledge through the proposed appointment of a clinical lead in MND
3. Independence - working with the Department of Health on a national wheelchair delivery model.

The results of the UK survey have relevance to Australia confirming feedback from our members regarding the importance of supporting research, providing care and support and educating health professionals.

Israel



Efrat Carmi, CEO, reported on the progress of the Patient Care and Support Department. The association was established in 2004 with the initial goal to support and drive research. In 2008 developing care and support for people living with MND also became a priority.

It is estimated that there are about 600-700 people living with MND in Israel and about 310 people living with MND are registered with the association. Since Efrat embarked on this program, the organization has developed a 24-hour hotline for patients to speak with a neurologist and a care professional and has developed a course for people recently diagnosed and their families.

Kathy Mitchell visited Israel during the year to help train and educate nurses

and other health professionals.

MND Australia has since provided information on the Information sessions for people recently diagnosed and their family and friends first established in Australia in 1998.

Efrat also reported on their very successful awareness campaign whereby mannequins were erected along the sea front in Tel Aviv to represent all the people who had died from MND over the last 12 months.

www.israls.org.il



Belgium

Evy Reviere reported on the 15 Years of the ALS Liga Belgium and what they would like to achieve in the future. Achievements to date include establishing an annual conference for

people living with MND and health professionals. This year the Alliance supported this major event with both Donna Corbett and Kathy Mitchell attending.

Their program providing equipment has been a great success. People over 65 years cannot access equipment from the government so equipment has been a major focus for the organisation. They have now collected so much equipment that they are seeking to donate some of those items to other countries in need.

They continue to focus on raising funds to build a National ALS Care Centre and to date they have raised more than \$2 million of the \$4 million goal. The construction of such a facility would be the first of its kind in that country providing inpatient respite care and would be connected to the Belgian ALS Organization as well as hospitals and universities.

www.alsliga.be

Strategic Planning Workshop

Five of the round tables were allocated one of the themes identified as part of the strategic planning review:

- 1) mission and vision
- 2) membership levels/fee structure
- 3) awareness/marketing/communications
- 4) partnerships/programs etc
- 5) fundraising/grants/finance

Board members sat at each of the tables and members were asked to move around the tables and talk to the board about these themes.

A board member representing each theme reported back to the group as a whole. Notes have been made and the board will review all comments and discussion and report back to members during the year. The input from the membership will assist with the development of the draft strategic plan.

Update from ALS TDI



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.

Dr. Steve Perrin, CEO and CSO of ALS TDI, talked about this new era of drug development for ALS. He spoke about how biologists and chemists approach the challenge of drug development in very different ways and how each group has created new technology to further advance drug development efforts.

He also provided information about the Institute's leadership summit www.als.net/summit and the Young Faces of ALS Campaign www.als.net/youngfacesofals

In closing, Steve commented that the Alliance and all its members need to band together, because of its unique position, to create an international research effort. He offered to put together a proposal on how to move forward. ALS TDI's website is www.als.net and its patient forum is located at www.als.net/forum

New resource on respiratory management

Dee Norris introduced a new book by Lee Guion on Respiratory Management of ALS – available at www.jbpub.com. She talked about the emerging evidence regarding the use of non-invasive ventilation in improving the quality of life of people living with MND worldwide. By informing professionals about the evidence and resources such as this book, Dee hopes that clinicians will become more informed on how to prescribe and use non invasive ventilation. The Forbes Norris MDA/ALS Research and Treatment Centre has information available online at: www.cpmc.org/services/als

Incurable Optimist

The final speaker of the day was Steven Bell from the MND Association of England, Wales and Northern Ireland. 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 they 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. MND spread their 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 the association wanted to show these real people, each with an amazing story of courage and hope for the future, with the aim of inspiring more people to help.

The campaign has gained momentum using social media tools such as Facebook and Twitter. Patrick's blog is located online at www.patricktheoptimist.org

Steve invited the worldwide community to get on board to find their own incurable optimists or to initiate a worldwide incurable optimist movement. We will be looking at how we could implement incurable optimist activities in Australia during 2011.

'Warm and Fuzzy' Dinner

That night there was a dinner for all of the Alliance members hosted by Gudjon. At dinner Gudjon recognized Allan Graham for his 10 years of service to the Alliance. Graham Opie, CEO MND NSW, spoke on behalf of the Australian contingent inviting all Alliance members to Sydney next year.

Thursday 9 December - Partnership Program Updates

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



Kathy Mitchell presented on her growing education outreach and partnerships. Building on previous successes in Europe Kathy visited the Malta Hospice group, the Cyprus Institute of Neurology, the Israel ALS Association and Belgium ALS Liga during 2010. By sharing expertise and a willingness to collaborate Kathy aims to 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. Kathy aims to address the needs of the country and the people living with MND. Kathy also aims to provide sustainable support by increasing the knowledge of the health

professionals involved in MND care and through the provision of resources and online information.

The English / Turkish Partnership

For the last 3 years the International Alliance of ALS/MND has supported two Care Centre Coordinators from England, Rachael Marsden and Jan Clarke, to work with Professor Coskun Ozdemir from the Association of Neuromuscular Disorders of Turkey. Their original visit entailed educating nurses involved in caring for people with MND. Their concern was that this would not be sustainable.

In 2009 a chance meeting with Lembit Opek MP led to an invitation to the Turkish embassy and a visit to Ankara to introduce the concept of the Care Centre program to the Turkish government. In 2010 Professor Coskun Ozdemir was invited to meet with the Turkish Minister for Health to talk about MND. This has led to increasing support from the Government in the provision of training for general practitioners and developing the role of nursing staff in local hospitals to coordinate MND specific care.

In October Rachael and Jan organized a 5 day intensive course for 23 nurses from all around Istanbul. The course encouraged nurses to take charge and to make changes. In January 2011 15 nurses will visit the UK to visit hospices, MND care centres and to attend an advanced study day. They are hoping the International ALS/MND Symposium will be held in Turkey in 2013.

Sharing the care experience of ALS/MND between the strait

This talk was yet another example of how alliance members work together to improve the lives of people living with MND worldwide. There has been a MND association in Taiwan since 1997. Dr. Ching Piao provided a review of the Annual Conference that his organization has created in the region over the past few years and how that event has helped to build bridges between his country and colleagues in China.

China has to date had no official ALS/MND organization. Increasing conversations between Dr. Ching Piao and China led to the first Beijing Symposium on ALS on 20 June 2010 and the first Association Patient Support Group event in China. On 21 June 2010, ALS/MND global day, patients and their caregivers from Taiwan and China gathered together to attend the 2010 Expo in Shanghai China, they shared experiences and provided each other with support.



Dr. Min Huang, co-presenter, is the Vice General Secretary of the Chinese ALS Committee. Dr. Huang showed a video to introduce the work done by her organisation and spoke about their aim to use television and other advertising strategies to improve information about MND in China. The Chinese ALS Committee already has 3000 members and anticipates that this number could increase dramatically as they become better known. They wish to develop a patient register. MND Australia will send information on AMNDR to Dr Huang in the New Year.

Taiwan MND Association www.mnda.org.tw
China ALS Committee www.jdr.cmda.org.cn

Mr. Yoshiyuki Fujisawa - A Positive Life



Mrs Fujisawa read out an inspiring speech written by her husband using his high tech communication devices attached to his wheelchair. He talked about his own experience of living with MND and his decision to live as long as possible. He explained how he has focused on making a difference by using his network of friends and colleagues to increase understanding of MND in Japan. He also talked about the ways in which people like him keep a positive attitude as part of their approach to fighting the disease. Mr Fujisawa was accompanied by his four full-time personal care assistants.

International Medicine Paulo Gontijo Award and Project TODOS POR ELA, a Brazilian digital journal specially made for ALS patients.

The final member update was provided by the Brazilian delegates Marcela Gontijo and her colleague from ABrELA. The PG award is open to researchers, students and professionals researching MND. The first PG Award was given in 2007 and in 2009 the number of applicants had increased by 400%.

Applications for the next PG Award are now open and the successful applicant will be announced in 2011 in Sydney at the 22nd International Symposium ALS/MND. The PG Award consists of US\$20,000 and a gold medal.

To apply see www.ipg.org.br



They also reported on a new online resource, “Todos por ela” developed for the Portuguese speaking world. The online resource provides information on MND for people living with MND, families and health providers – all in one place. Sounds a bit like MNDcare in Portuguese!

RNA is now in the Spotlight

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

Jeff's presentation provided a 'plain English' – well almost – overview of terms, mechanisms and jargon surrounding RNA. Jeff reported that the biopharmaceutical industry is abuzz with attempts to harness the power of the 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?

He referred to research related to MND and RNA as the Quiet Revolution and suggested that developing RNA research could lead to therapeutics using gene therapy, stem cells and RNA interference.



Sydney 2011

The final presentation as always is dedicated to promoting the following year's meetings to Alliance members. Carol Birks MND Australia provided information on Sydney and showed a promotional DVD kindly supplied by Business Events Sydney. There was a general positive response to the warm November weather in Australia and the wonderful scenery on offer!

Australian attendees Carol Birks, Sue Colyer, David Ali and Graham Opie, pictured above, Rod Harris (who took the photo) and Ralph Warren were actively promoting Sydney 2011 throughout all the meetings.

Attending these Alliance meetings is invaluable in hearing about how other countries support people living with MND and although this is not always applicable to Australia thoughts are stimulated and ideas are shared. This all helps us to understand and put into context achievements and constraints in supporting people living with MND in Australia.

Ask the Experts

The Ask the Experts session always follows on the afternoon of the second day of Alliance meetings. This event was organised by the host association, ALSA, and sponsored and supported by the ALS Hope Foundation and the International ALS/MND Alliance.



This session is aimed at people living with MND and their family and friends and was very well attended. The session involves a series of short presentations with an opportunity for the audience to ask questions of the expert. At the conclusion of the session all speakers are available as a panel for further questions. Speakers this year covered a range of interesting topics:



Solving One of History's Great Mysteries: Why Are So Few Patients Enrolling in ALS Research Studies?

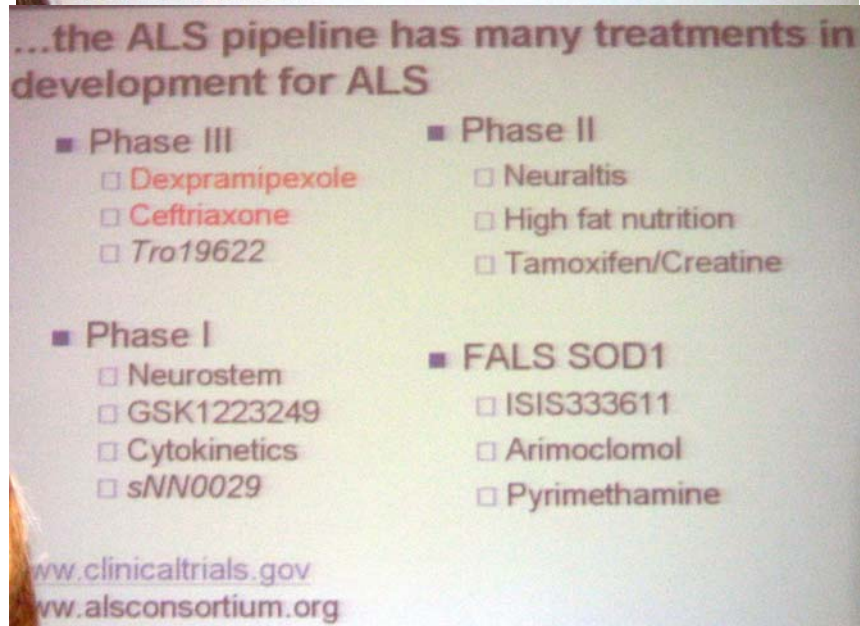
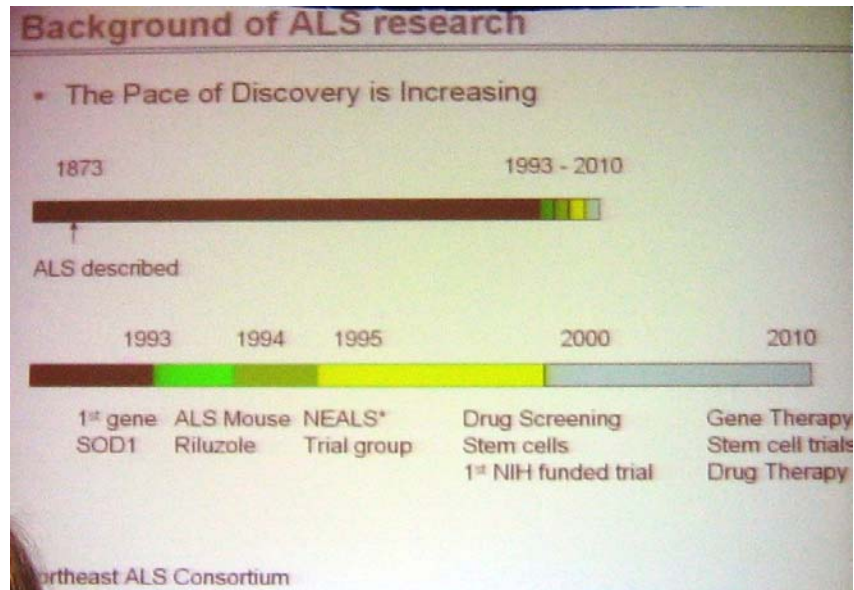
Richard S. Bedlack M.D., Ph.D., FAAN, Duke University ALS Clinic www.dukealsclinic.com

Current ALS Therapeutics in Clinical Trial

Merit Cudkowicz, M.D., MSc., Director of the ALS Clinic at Mass General Hospital, Co - Founder NEALS

www.alsconsortium.org/Navigatingclinicaltrials.gov.html

www.als.net/OurResearch/ClinicalTrials.aspx.



Human Neural Stem Cell Transplantation for the Treatment of ALS

Nicholas Boulis M.D., Neurosurgeon, Emory University,



<http://www.neurosurgery.emory.edu/FacultyBoulis>

Genetics of ALS – what’s new and what’s next?

Rosa Rademakers, Ph.D., Independent Investigator, Mayo Clinic, Jacksonville, FL

The presentation on Stem Cell transplantation was particularly interesting highlighting the complexities of this technique and an overview of the first clinical trial underway in the USA.

These presentations will be available online via the alliance website at www.alsmndalliance.org

MND Australia will be responsible for developing the program for the Ask the Experts session in 2011 and for promoting this event to members nationally. We hope to be able to invite national and international speakers to attend and we will look into the possibility of recording or even live streaming this event to members.

Host Dinner

That evening the hosts ALSA invited all Alliance meeting attendees to the host dinner at Sea World. The venue provided those of us who did not leave the hotel for the six days of meetings to a taste of the Orlando theme parks! We were treated to a visit to the aquarium and dinner with the sharks! It was a wonderful evening of friendship and laughter.

MND Australia will be responsible for organizing the host dinner to showcase Sydney in 2011 and we are currently busy looking at suitable venues with MND NSW.

Allied Professionals Forum – 10 December

This forum is hosted by the International ALS/MND Alliance and as always attracted many health professionals and quality presentations related to the care and management of MND. This day provides unique opportunities for networking and discussion with colleagues from overseas. Presentations from Australia included one from Carol Birks on the MNDcare website and one from Rod Harris on 'Take a break from MND'.

Highlights from the 17 presentations included a wonderful talk on the impact of equipment on relationships from Bridget Taylor, Oxford, England whose PhD research combines her two areas of speciality sexuality and life limiting diseases. Her talk highlighted that many pieces of equipment hinder communication and connection between people living with MND and their partners. Talks from our USA colleagues on the emergence of incorporating palliative care into MND care in the US highlighted the progress that Australia has made in our interdisciplinary approach to MND care. Dr David Oliver made two presentations one on cognitive change and one on withdrawal of Non invasive ventilation. David has very kindly made these presentations available for the MNDcare website.

Abstracts will be available on the International Alliance website if you would like more details on these presentations: www.alsmndalliance.org

The Allied Professionals Forum will be held at the Hilton Hotel on 29 November and will be a unique opportunity for Australian MND association staff and health and community care professionals to showcase Australian models of care and innovations to the international MND/ALS community. Carol Birks and Rod Harris are on the APF program committee and call for abstracts will be sent around early in 2011.



The International ALS/MND Symposium – 11 to 13 December

The 21st International ALS/MND Symposium was hosted by ALS Association of America (ALSA) and organised by the MND Association of England, Northern Ireland and Wales. The meetings ran over three days from the 11 to 13 December and presented latest research related to clinical care and science. The symposium attracted over 800 delegates with many Australians in attendance. Platform presentations included Australians Julie Atkin, Rod Harris (MND Victoria) and Sue Colyer (MNDWA). Many other Australian researchers and clinicians presented posters on their work including a poster on the MNDcare website.

This year although there were no major breakthroughs the depth and breath of research was once again quite astounding. The Joint Opening Session commenced with a presentation on *New Perspective on ALS as TDP-43 proteinopathies* from V.Lee (USA) and *AAN practice parameters: What they tell us and what they don't* from R.Miller (USA).

Dr Miller highlighted the progress in MND care. In the 1980's people were told to go home and put their affairs in order, in the 1990's riluzole became available as a therapeutic, the 2000's saw the emerging use of non invasive ventilation and PEG as interventions and the importance of early diagnosis became apparent. Now in 2010, evidenced through a number of Cochrane Reviews and the AAN Practice Parameters, we can tell people diagnosed with MND that although the disease is not curable it is treatable. Dr Miller pointed out where evidence remains lacking and the need for more high-quality, controlled studies to guide management and assess outcomes in patients with MND. Dr Miller also highlighted the persistent underutilization of evidence based interventions in the US with only 63% of people with MND taking Riluzole, 21% using non invasive ventilation and 9% with a PEG.

As a matter of interest Penny Waterson, MND NSW, through her work on the MNDcare website was invited to contribute to Cochrane Reviews as a consumer representative. She attended the Cochrane meeting whilst in Orlando as a MND Australia Travel Grant recipient.

Concurrent sessions over the three days covered a wide range of scientific and clinical research. The presentation *Palliative Care in terminal illness; impact on healthcare professionals* from V. Jackson (USA) was particularly interesting and relevant for MND association staff. She discussed compassion fatigue and how to recognise the signs and symptoms of an unsustainable work load and the complexities of supporting people at and of life. She highlighted the importance of being self aware and maintaining professional boundaries.

There were many more interesting presentations and all the abstracts are available at the following link:

http://www.mndassociation.org/research/for_researchers/international_symposium/21st_international_symposium_on_alsmnd/21st_international.html

This year the organisers decided not to hold a Symposium Dinner and in its place held a cheese and wine poster evening. At this event the Aussies were out in force promoting Sydney 2011. MND Association staff, Nina Buscombe Award recipients and Australian scientists distributed clip on Koalas provided by Business Events Sydney to delegates as they entered the room asking them to bring the Koala's home to Sydney next year! After some initial reticence delegates were soon coming back asking for more Koalas's to take home to children and grandchildren and the room was awash with people wearing clip on Koala's!

The joint closing session commenced with Ralph Warren, President MND Australia, formally inviting delegates to the 22nd International ALS/MND Symposium in Sydney. The film showcasing Sydney was shown and Ralph provided a warm and welcoming overview of Sydney and its surrounds.

Closing session overview taken from the Symposium Blogsite:

<http://mndresearch.wordpress.com/category/symposium/orlando-reporting/>

The closing session begins with 'late breaking news'. This is an exciting opportunity for very new and exciting results to be explained to all delegates.

Dr Bryan Traynor, who is a genetic researcher based at the National Institute for Health in Maryland, America was first to take to the stage. Last week, Dr Traynor and colleagues released their finding that a new causative gene for MND had been identified. This is the third to be discovered this year alone, which demonstrates the immense speed that MND genetic research is moving. In the talk, Dr Traynor described his recent findings. The gene is called VCP, which stands for 'Vallicin-Containing Protein'. It was first discovered by Bryan's group in a family affected by inherited (familial) MND and was soon verified as a cause of the disease for other people with familial MND. They speculate that VCP is the cause of MND for 2% of cases of familial MND. For more information on what this finding means to people affected by MND, please read our press release on our website.

Through Bryan's talk, we also heard that this particular gene is found on chromosome 9. A chromosome is an organisational structure for our genetic code – as humans, we have 23 pairs numbered 1 to 22 with the final pair being the sex chromosomes (XX or XY). The news that VCP is on chromosome 9 is an interesting one given that earlier this year a study, led by Prof Ammar Al-Chalabi – an MND Association funded researcher, at King's College London found a region of DNA within chromosome 9 that contains three genes that may be associated with the randomly occurring sporadic form of MND; a condition called 'fronto-temporal dementia' (FTD) that affects behaviour, emotional response and language skills; as well as a rare inherited form of MND called MND-FTD.

However, it is important to note that the genetic regions are not the same, they are just found on the same 'street' of the chromosome. An interesting co-incidence none-the-less!

Prof Ammar Al-Chalabi next took to the stage with a talk entitled: What else is hiding in Chromosome 9. In his talk he discussed the reasons why finding the exact underlying genetic cause of MND-FTD in chromosome 9 is so difficult.

As the symposium draws to a close, Prof Nigel Leigh gives the final scheduled talk. Prof Leigh is an eminent researcher and clinician and is arguably one of the forefathers of MND research and care – especially in the UK. Throughout his career he has made many important discoveries, founded the first UK MND care centre and inspired many young clinicians and researchers – many of whom are now eminent researchers themselves.

In his talk, Prof Leigh discussed the classifications of MND – such as PLS, flail arm, bulbar etc, and the notion that this way of thinking is out of date. To explain this, in his abstract he poetically wrote that "just as classical notions of the constellations and galaxies tell us little about astrophysics, so the identification of phenotypes (clinical symptoms) with theory may be more fanciful than helpful". This refers to the fact that the presentation of MND does not tell us anything about what is happening inside the body. With our growing knowledge in genetics and biomarkers for MND, this may start to change.

He finishes by calling for a new consensus on the classifications of forms of MND.

It was an intense three days which highlighted the commitment, collaboration and passion of researchers, clinicians and care providers in finding the cause, effective treatments and better management strategies and ultimately a cure for this disease. It is only through sharing this knowledge and collaborating internationally that we can find a new treatment for MND and improve care and quality of life for all who are living with the disease.



The ALS/MND Alliance Meetings and Symposium will commence 27 November through to 2 December at the Hilton Hotel.



Sydney 2011

We look forward to welcoming the international ALS/MND community to Sydney in 2011.

Carol Birks, National Executive Director, MND Australia