



Report on the 16th Annual Meeting of the International Alliance of ALS/MND Associations and 19th International Symposium on ALS/MND

As one of the MND Australia delegates to the International Alliance of ALS/MND Associations I was fortunate to attend their 16th meeting in Birmingham, UK on 31 October and 1 November. The venue was particularly significant for some of the founding members present who reflected that the first meetings to form the Alliance had been held just down the road in Solihull. The Alliance has grown considerably during this time to a membership of 49 organisations representing 40 countries. There were 63 delegates and observers present at the meeting.

The meetings commenced with the AGM where Rod Harris, CEO MND Victoria and MND Australia delegate, stood down as the Chairperson and handed over to Gudjon Sigurdsson from Iceland. Rod's achievements in growing and developing the Alliance were formally recognised and acknowledged by the board.

Presentations on the first day provided an overview of care and information developments in Iceland, Taiwan, Italy, Slovenia, Australia, Israel and Spain. Contrasting awareness films from the UK and Canada were shown which engendered much discussion. There was a short introduction to the film "Living with Lew" presented by Dee Holden Norris. This film follows a young Hollywood writer and director who received funds to direct one of his films after being diagnosed with MND. The film follows his life as he directs the film from his wheelchair. Hopefully this will be shown in Australia one day!

Promoting Global research and collaborations was a theme during the day with a presentation from the Paulo Gontijo Institute to promote their PG Award. Researchers or scientists from anywhere in the World can apply for this funding in 2009. The Israeli Association (IsrA.L.S) were inspiring in outlining their achievements and goals since they were founded just four years ago. Three years ago there was no ALS research in Israel and now the Association is funding 20 researchers. They have been instrumental in initiating a national research program of neurodegenerative diseases and have secured matched funding from their government. IsrA.L.S is keen to promote combined global research efforts.

The next day provided updates on two Alliance initiatives - the Partnership Program and Needs and Offers. The Partnership Program is supported by the Alliance Support Grant Program which provides monetary assistance to support less well resourced Associations or to help establish new Associations around the world. 37 support grants have been awarded since it was established five years ago.

Kathy Mitchell from Algonquin College in Canada has been working closely with the ALS/MND Association in Serbia/ Montenegro over the last 5 years educating and supporting health professionals caring for people with MND. The ongoing partnership between the ALS Hope Foundation, USA and ABrELA, Brazil, has been further strengthened through exchange visits to promote sharing of information and ideas. A new partnership was established during the year between England and Turkey. Turkey has limited resources for people living with MND and the professionals caring for them. Two nurses from England visited Turkey to provide MND education and support to the nurses there. They plan to remain in contact via email and to visit the Turkish health minister to discuss their project and the model of care in the UK.



Needs and Offers were established last year to promote sharing of resources, information and ideas. During the year Iceland identified the need for a database to organise information about people with MND in Iceland – The ALS Hope Foundation offered to provide theirs and an

exchange visit facilitated further sharing. At the meeting in 2007 IsrA.L.S offered a DVD featuring Professor Stephen Hawking to all Alliance members. MND Australia needed a community service announcement to support the MND Week 2008 theme Living Better for Longer and used the DVD to fill this need. The UK/Turkish partnership grew from the Turkish need for health provider education and support and the offer from the UK nurses to provide support. This program, along with the Alliance itself, continues to grow and develop.

The Ask the Experts session was held that afternoon for people living with MND and this year a new format was trialled based on speed dating!! Over 80 attendees sat at tables and the researchers moved every 10 minutes to a new table to talk about their research and to answer questions.

The Allied Professionals Forum, hosted by the International Alliance, precedes the Symposium and as always attracted many health professionals and quality presentations related to care and management of MND. There were 15 presentations including three from Australia. Management and care issues covered included: care pathways, a fast track diagnosis program, volunteers and the multidisciplinary team, nurse led clinics, compassion fatigue, support needs of people with MND, palliative care, the computer and communication, guidelines on PEG placement and diaphragm pacing to assist breathing. Abstracts will be available soon on the International Alliance website if you would like more details on these presentations: <http://www.alsmndalliance.org/meetings.html>

The Symposium, hosted and organised by the MND Association of England, Northern Ireland and Wales, was held on the following three days and included plenary sessions, concurrent scientific and clinical sessions and a room filled with research posters! As Brian Dickie, Director of Research at MND England, Northern Ireland and Wales commented “after more than 60 years of research ALS/MND research around the world is now exploding”. There were many interesting presentations and all the abstracts are available at the following link: http://www.mndassociation.org/research/for_researchers/international_symposium/19th_international_symposium/abstract_book.html

I attended the clinical sessions and there were many useful presentations which will help to strengthen our quest to promote the best possible care and support for people living with MND in Australia. Work being done to identify the different types of MND is progressing. This research is vital in ensuring an early and accurate diagnosis for people with MND, to guide treatment, to develop disease markers and to assist physicians to provide a more accurate prognosis to their patients. The increasing need for evidence based research related to MND care management was highlighted and the difficulties discussed. Although evidence based treatment trials are the “gold standard” the presenter argued that there should be an opportunity to also share the experiences of pro-active multidisciplinary teams that commonly utilise non- evidence based symptomatic treatments to improve quality of life and comfort.

The diagnosis of MND can sometimes take a long time delaying the initiation of support and treatment. An MND care centre in the UK implemented a fast track referral process for people suspected of having MND. The median time from referral to diagnosis for the fast track patients was 51 days and 104.5 days for the non fast track patients. The most important barrier to early diagnosis is the ability of the GP to identify MND as a potential diagnosis.



The importance of ALS/MND registries in defining clinical characteristics and care provision was discussed by a researcher from an ALS centre in Italy. Their register of ALS/MND patients has shown no increase in incidence since 1995. A significant decrease in the time from symptom onset to diagnosis during this time indicates that physicians in the area are more aware of ALS/MND. Please talk to your neurologist about registering with the Australian MND Registry (AMNDR) www.amndr.org if you are not already registered and contribute to Australian research.

A Spanish survey of patients experiences of diagnosis and care identified that there was considerable delay in diagnosis and that this delay and the way the diagnosis was given impacted on the emotional distress of the patients. The need to raise awareness of MND and to educate health professionals was confirmed.

There was a whole session on cognitive and psychological change demonstrating that research related to this symptom has progressed considerably. The prevalence of frontotemporal dementia in the ALS population is estimated to be up to 50%. How this manifests in individuals, however, varies considerably from very minor and subtle behavioural changes or word finding difficulties to, in a very few cases, a marked dementia. Evaluation and screening is therefore important but often very difficult. The development of concise and practical assessment tools to assist multidisciplinary teams to improve care planning and support with the patient and the family is progressing. The need to better understand the impact of cognitive change on the quality of life of the person with MND and the carer and to invest in appropriate information and clinical resources was also discussed.

The Respiratory Management session discussed the need for optimal timing of this intervention based on ventilatory insufficiency and also the issue of compliance. The presenters highlighted that we know that non invasive ventilation extends survival and improves quality of life but that many people do not tolerate this intervention or refuse it when offered. It has been suggested that early initiation may assist with compliance, but there is no standardised method for initiation to guide practice. A number of trials are looking at these issues. One study suggests that males with a higher level of income and education and good upper limb function are more compliant. The importance of education and support to manage the non invasive ventilation machines and to address issues was highlighted. A new technology to stimulate the diaphragm to assist respiration being trialled at 11 sites worldwide was presented. Diaphragm pacing involves the insertion of pacing wires into the diaphragm to stimulate contraction of the diaphragm in patients who are experiencing diaphragmatic weakness which impacts their breathing. This trial has found that the technology is safe, has a positive effect on diaphragm function and enhances non invasive ventilation use. It was found to be most useful for people with more upper motor neurone involvement.

The final joint closing sessions included the scientific highlights. In this session research advances related to axonal transport and new genes were discussed. The potential for research advances to be further investigated using new animal models, including a fly model, was highlighted. Results of a randomised control phase II trial for Coenzyme Q10 showed a decline in function for those participants who were given the drug. Delta 9Tetrahydrocannabinol was found not to be effective in treating cramps. A two year multicentre trial to assess the efficacy of subcutaneous Insulin-like growth factor type 1 (IGF-1) found no difference between treatment groups. Current drug trials are focussing on testing drugs that can get into the cerebral-spinal fluid and a couple of preliminary drug trials are looking promising.



It was a positive end to a very intense few days for all delegates to note that a new genetic cause has been identified that we knew nothing about 12 months previously resulting in a whole session on TDP 43 related research. There are now increased insights into the genetic causes of sporadic ALS and the mutant SOD 1 mouse model is being refined to be a more effective research tool.

Although there were no major breakthroughs related to treatments for people living with MND today the increased understanding of many of the mechanisms related to MND provides hope that we are getting closer to that breakthrough. In the meantime clinical research confirms the positive effect of early diagnosis, comprehensive multidisciplinary care and management interventions to assist nutrition, ventilation and communication on quality and length of life for people living with MND.

The International Alliance of ALS/MND Associations promotes both care and research internationally. This is confirmed by the two awards presented annually at the Symposium Dinner. The Forbes Norris Award, first presented in 1994, was inaugurated by the International Alliance of ALS/MND Associations in memory of Dr Forbes (Ted) Norris a neurologist dedicated to helping people with ALS/MND. The Award is to encourage a combination of two major qualities, management of, and advances in understanding ALS/MND, to the benefit of people living with ALS/MND. The recipient this year was Canadian researcher Michael Strong. The Humanitarian Award was inaugurated in 2000 by the International Alliance of ALS/MND Associations to recognise non-scientific contribution to the fight against ALS/MND. The award recognises and encourages individuals from a non-scientific background whose work makes, or has made a contribution of international significance for people affected by ALS/MND. I am very pleased to report that this year an Australian, Rodney Harris, CEO MND Victoria and outgoing chair of the International Alliance, was presented with this prestigious award in recognition of his work both nationally and internationally.

Once again this year an Australian person with MND, Mr Phil Brady, was included in the International March of Faces Banner. There is one Australian featured on most of the banners so if you would like to be included on the new banner next year please contact me as soon as possible.

The 2009 International ALS/MND Alliance Meetings and Symposium will run from 4-10 December in Berlin, Germany.

Carol Birks, National Executive Director, MND Australia