

Report on the 17th Annual Meeting of the International Alliance of ALS/MND Associations and 20th International Symposium on ALS/MND

David Ali, Vice President MND Australia, and I attended the 17th meeting of the International Alliance of ALS/MND Associations in Berlin, Germany on 5 and 6 December 2009 as the MND Australia delegates. 21 member Associations from 22 countries were represented by a record number of 89 delegates and observers.



The meetings commenced with the AGM chaired by the President Gudjon Sigurdsson from Iceland. The general meeting followed with 14 presentations from nine different countries including Australia. There were some very powerful and moving presentations. Denmark highlighted their active welfare system that allows people with disabilities, including those living with MND, to remain in control of their own lives with assistance from full time helpers. Also from Denmark were presentations on 'Speaking with the eyes', demonstrating that communication using a letter board can be very quick and effective, and another highlighting inequities related to access to non invasive ventilation in Scandinavia. Associations from the USA, Scotland, Japan and Italy provided an overview of care initiatives developed during the year.

The Muscular Dystrophy Association ALS Division reported that they had allocated US\$38 million to ALS research and that this funding was available worldwide. They are currently funding 350 research projects. Steve Perrin, Chief Scientific Officer at ALS Therapy Development Institute (ALS TDI) highlighted the background to ALS TDI and gave an update on the Institute's research efforts he also spoke of the process and progress being made toward the development of therapeutics for ALS patients, which is available at <http://www.als.net/>.

Innovative awareness and fundraising initiatives were reported. In Spain the Association has produced a video based on the daily life of 34 year old man living with MND entitled '4000 screams' to represent the 4000 people living with MND in Spain. ALS Canada presented a background to their 'Heads and shoulders, knees and toes' public service announcement which was very successful and won a number of industry awards. ALS Israel then spoke about "Fundraising out of the Box", and explained that IsrALS had raised funds by using the "paperclip effect" auctioning one object for another. This campaign had started with auctioning, via the website, underwear for a guitar, the guitar, for a climbing adventure, the climbing adventure for computer lesson and so forth until \$50,000 had been raised!

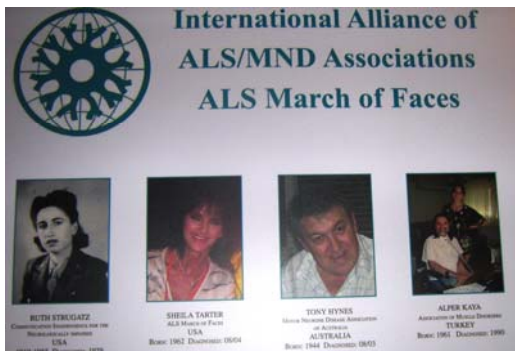
In my presentation I shared the Australian initiatives undertaken in 2009 and included a short excerpt from the film 'Glass half full living with motor neurone disease'. I also made a request for Alliance members to support the national project to develop a new website to support health and community providers to assist people living with MND to live better for longer through the provision of easily accessible online information. This project is funded by the Commonwealth Department of Health and Ageing.

Presentations continued the next day with an update from Professor Kathy Mitchell from Canada on her work in Eastern Europe. Updates from Taiwan, and Brazil followed. The morning ended with a presentation from Jeffrey Deitch, the Executive Director of the ALS Hope Foundation who led a discussion on the topic of how to answer the question, 'Is there any progress in finding a cure?'. The discussion highlighted the difficulties in reporting the progress in research, and tempering these breakthroughs and how they relate to people living with MND now, whilst still providing hope.

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.

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. Professor Christopher Shaw of the UK was awarded the Forbes Norris Award 2009. As a physician Professor Shaw's dedication to patient care, his visionary approach to research and his tireless promotion of the interests of people with the disease are an inspiration to the whole ALS/MND community.

Professor Kathy Mitchell was awarded the Humanitarian Award 2009. Kathy has invested her time, energy and resources to improving the education of allied health and nursing professionals in Eastern Europe, Turkey and Peru about ALS/MND. Kathy is a true humanitarian and a valued member of the International ALS/MND Alliance.



Once again this year an Australian living with MND, Mr Tony Hynes, 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 for 2010 please contact me as soon as possible.

The Allied Professionals Forum, on the day preceding the Symposium, as always attracted many health professionals and quality presentations related to care and management of MND. This forum provides

unique opportunities for networking and discussion with colleagues from overseas. Presentations from Australia included two from Maryanne McPhee, Speech Pathologist from Calvary Health Care Bethlehem, who spoke about the Victorian Pathways Project and communication options for people with MND. A joint paper from Kristina Dodds, HOME Hospice and Josephine Fowler, MND NSW, discussed their partnership whereby carers of people with MND are matched with a HOME Hospice Community mentor. I also presented on the Confident Caring Project conducted in Queensland during 2008/09. If you would like more details on these presentations, abstracts are available on the International Alliance website at: <http://www.alsmndalliance.org/index.php?page=74>

The 20th International Symposium on ALS/MND was held over 8 - 10 December and hosted by Deutsche Gesellschaft für Muskelkranke of Germany and organised by the MND Association of England, Northern Ireland and Wales. It presented latest research related to clinical care and science. There were many interesting presentations and all the abstracts are available at the following link:

http://www.mndassociation.org/research/for_researchers/international_symposium/20th_international_symposium_on_alsmnd/abstract_book_2009.html



The symposium attracted a record number of 900 delegates with 33 Australians in attendance. Dr Robyn Ray, James Cook University, Queensland, spoke about "*Managing death in ALS/MND: identifying carers perspectives of the final days of life*", Professor Matthew Kiernan, Prince of Wales Hospital, University of NSW, presented on "*Understanding the Pathophysiology of ALS*", Adam Walker and Julie Atkin, Howard Florey Institute, University of Melbourne presented their current research and many other Australian researchers and clinicians presented posters on their work.

Although there were no major breakthroughs this year, the depth and breadth of research undertaken was quite astounding. There were reports on two drugs that have shown to slow the progression of the disease that are now advancing to phase III trials in North America and Europe. There was a general air of hope and excitement about the future of MND care and research.

The closing session was very hopeful and Dr Meyer, who summarised the clinical sessions said that this year, he had seen a trend in the evidence for symptomatic treatment and care; an improvement in palliative care; progress in clinical trials and trial management; an integration of information technology in trials, patient management and home care as well as the empowerment of patients and their families.

Dr Van den Bosch summarised the scientific sessions and he confirmed that it is exciting times for MND research. He stated that fifteen years ago, we learnt about a mistake (mutation) in a gene called SOD1 that causes 20% of the inherited, familial form of MND (the familial form accounts for 10% of all cases of MND). A few years later, he said, we then developed riluzole, the first and only treatment for MND. In the past two years, we have learnt about two new causes of inherited MND, the TDP-43 and FUS gene mutations. During the symposium we also learnt more about the role that genes play in MND as well as the development of a number of new and exciting animal models and more about the causes. He concluded that we are constantly adding to our current knowledge.

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, 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 2010 International ALS/MND Alliance Meetings and Symposium will be hosted by ALS America (ALSA) from 8 to the 13 December in Orlando, Florida.

The 2011 ALS/MND Alliance Meetings and Symposium will be held in Australia in early November hosted by MND Australia.

Carol Birks, National Executive Director, MND Australia