International Meetings, Dublin, 2016

The Annual International ALS/MND meetings are organised by the MND Association of England, Wales and Northern Ireland in partnership with the International Alliance of ALS/MND Associations. Experts from research and medical communities as well as ALS/MND associations and people living with ALS/MND come together each year to share new understandings about ALS/MND to improve the lives of people living with ALS/MND. All share a common goal to move us closer to finding effective treatments and ultimately a cure. The Symposium is preceded by the International Alliance annual meeting, an Ask the Experts session and the Allied Professionals Forum. This year the meetings were held from the 4 to 9 December and hosted by Alliance member the Irish MND Association.

As I embark on my last year as Chairwoman I extend a warm welcome to new Director Rob Goldstein and congratulate Sara Feldman on her re-election for a second three year term. Barb Newhouse, CEO at The ALS Association, was nominated unopposed as the Chair – Elect at the AGM and I look forward to working with Barb during 2017 in preparation for her taking over as Chairwoman at the AGM in December.

24th Meeting of the International Alliance of ALS/MND Associations

With over 110 delegates from 30 countries across six continents attendance at the 24th meeting of the International Alliance of ALS/MND Associations was a record!

People living with ALS/MND are at the heart of everything Alliance members do. The aim of the Alliance Meeting therefore continues to be to promote partnerships and to provide ideas and information to assist members to improve outcomes for people living with ALS/MND in their respective countries.

The International Alliance of ALS/MND Associations awards travel grants every year to support members who would otherwise not be able to afford the cost of attendance. This year travel grants enabled Asha EK Hope Foundation (India), ALS Mongolia, MND Malaysia and the Cuban Institute of Neurology and Neurosurgery to attend the meeting.

During the meeting the GM, Rachel Patterson, gave a comprehensive overview of the work of the Alliance during 2016. In 2016 the Alliance admitted eight new associate and full members from USA, Rwanda, Bosnia Herzegovina, Romania and South Korea. The Alliance now has 54 members from 36 countries.
Overview of Key Presentations:

**Programming for PALS/CALS**

*Beyond Awareness Gaps* – Hiroki Okabe, Japan ALS Association, presented on a program to educate and train college students to provide personal care. This program has enabled people living with ALS/MND to take charge of their own care and to receive round the clock in-home care.

The Cost of Achieving Your Goals: Assistive Technology Program in Israel – Efrat Carmi, IsrALS, presented on their response to the challenges they faced following a successful hard fought advocacy campaign to convince the government to fund technology equipment.

A Comprehensive Information and Education Resource for People with MND, their Carers, Health and Community Care Providers - Gina Svolos, MND NSW, provided an overview of information resources available and the MND Aware, Living well with MND, Carer Education and Newly Diagnosed information and education sessions they provide. Audience expressed interest in sharing these great resources.

New Challenges to Our Association - Alessandra Dorca, ALS Pro-Cura Association, Brazil, provided an overview of the development of the organisation since its inception in June 2013 and the challenges of raising funds post Ice Bucket Challenge.

**Partnerships and Collaborations**

The cornerstone of the Alliance is its partnership and mentoring program. Presentations at the meeting highlighted positive outcomes from member partnerships developed following last year’s meeting and the benefits of associations adopting a collaborative partnership approach.

A Phased Shift in MND Care in Scotland – Craig Stockton, MND Scotland, presented on significant outcomes for people living with MND in Scotland as a result of their work and partnerships with the Scottish Government, the National Health Service, Universities, MND Scotland and people affected by MND. Under 65’s with a terminal illness are now entitled to free personal care in line with those over 65, people have a legal right to AAC equipment and support and the number of MND nurses has doubled.

Using the MND Association’s Experience to Promote Optimal Care and Support in Russia – Anna Kassianova, Martha-Mary Medical Centre “Miloserdie” reported on the positive outcomes of the invitation from the MND Association at the 2015 Alliance Meeting to visit them in Northampton to share ideas and resources.
The South African MND Caregiving Experience: Lessons Learned from a Cross-Country Collaboration – Melinda Kavanaugh, University of Wisconsin-Milwaukee, presented on a partnership between a US research team and MND South Africa supported by an Alliance Partnership Support Grant. Family caregivers in South Africa provide total care to people living with MND. This project is helping to develop support and information for family carers.

First Ever ALS Student Exchange – Jodi O’Donnell, Hope Loves Company, USA, presented their plan to visit MND Iceland in 2017 to introduce the Hope Loves Company Ambassador Program to young people in Iceland. This partnership will be part funded by an Alliance Partnership Support Grant.

Research and Science

The ALS Analyzer Mobile App: Engaging PALS in the Development of New ALS Monitoring Tools – Idit Ron, Prize4Life, Israel. This smartphone-based application is available to people living with MND worldwide to monitor their disease progression and has potential to contribute to global research.

PULSE – Christine Tabuenca, ARSLA, France, reported on a multidisciplinary study being undertaken in France involving the 18 ALS Centres and 1000 people living with ALS/MND.
Precision Medicine: How Can It Help Advance the Discovery of ALS Subtypes and Speed Drug Development? – Rob Goldstein, ALS Therapy Development Institute gave a fascinating presentation on ALS TDI’s precision medicine program highlighting why this is important and why now is the most hopeful time in his career.

Meeting the Research Communication Challenge: Our Experience – Sally Light, MND Association of England, Wales and N Ireland presented on how her organisation communicates research outcomes and the challenges they face in getting the balance right.

Scientific Update – Dr. David Taylor, ALS Canada concluded the research and science session with a comprehensive overview of the current state of research and the accelerating rate of progress. Highly recommended!

Strategic Planning Workshop

Each year the Alliance conducts a workshop to report on actions and outcomes during the year and to set goals for the following year based on the Objectives of the strategic plan. The Strategic Planning Workshop provided the opportunity to report on outcomes achieved in 2016 and for members to define actions and outcomes for 2017.

During the session Rob Goldstein presented preliminary results of a member survey to ascertain research investment. Next steps will be to validate data and create an overview paper for distribution.

See Appendix for link to all presentations.
Ask the Experts

The International Symposium offers the host organisation a unique opportunity to invite international ALS/MND experts to provide updates to people living with ALS/MND in their region. These sessions are recorded and live streamed so that people living with ALS/MND who are unable to attend can access the information online.

This year Dr. Jeremy Shefner, Dr. Jonathan and Prof. Jan Veldink, PhD of UMC Utrecht spoke about the current state and direction of drug clinical trials, stem cell treatment and gene therapy in ALS.

Clinical Trials in ALS/MND: Where Are We Now? Dr. Jeremy Shefner, MD, PhD Kemper and Ethel Marley Professor and Chair of Neurology and Senior Vice President of Barrow Neurological Institute

Stem Cells: The Hope and the Hype Dr. Jonathan Glass, MD Professor of Neurology and Pathology at Emory University School of Medicine; Director of the Emory ALS Clinic

Project MinE: The New Genetics of ALS/MND Dr. Jan H. Veldink, MD, PhD Professor of Neurology and Neurogenetics and Head of the Human Neurogenetics Unit at University Medical Center-Utrecht

Dr. Shefner summed up the general feeling in Dublin with the following quote “I feel much more optimistic about the spectrum of ways we're attacking this than I ever have been before”. He also highlighted to the audience that the answers to even the most difficult, complex questions about ALS/MND are within our reach, but require more time, more research, and most of all, more money.

Watch the YouTube video of the 2016 Ask the Experts session: 2016 Ask the Experts

13th Annual Allied Professionals Forum

The Allied Professionals Forum enables the sharing of ALS/MND care and support innovations to help guide practice worldwide. Over 250 delegates attended to hear 16 presentations covering a wide variety of topics. The topics covered included carer and family support, swallowing, withdrawal of respiratory support and innovative approaches to assistive technology provision including the growing trend of voice banking.

Australia featured with a presentation entitled I Can Do It: The Impact of a One-Day Training Intervention on Occupational Therapist and Speech Pathologist Confidence in Working with Assistive Technology for Clients with ALS/MND from Kristina Dodds the Education and Carer Support Coordinator at MND NSW.

This year the meeting kicked off with recognition of Rod Harris’, CEO MND Victoria, contribution to the APF over the last 14 years. Rod was integral to the establishment of the APF and was a co-chair for 14 years before stepping down last year.

A new addition was the announcement of The ALS Assistive Technology Challenge: Winners. The technology challenge was funded by The ALS Association and Prize for Life to encourage initiatives to improve communication to help people living with ALS/MND have a voice. 87 groups from 16 Countries submitted ideas. Five teams were awarded seed funding to develop their ideas which were presented to judges and people living with ALS/MND the day before the APF. This presentation includes an overview of the assistive technology developed by each of the finalists.

Each year the quality of the presentations improves and this year was no exception. The presentations provide take home messages and ideas to stimulate discussion and assist those involved in the care and support of people living with ALS/MND to reflect on their own practice and perhaps initiate change to better meet the needs of the people living with ALS/MND that they care for. Links to all presentations are included in the Appendix.
The International Symposium is the largest medical and scientific conference on ALS/MND. It is the premier event in the ALS/MND research calendar, attracting a record 1100 delegates this year, representing the energy and dynamism of the global MND research community.

Mary Robinson, Chancellor of Trinity College and past President of Ireland, kicked off the 2016 Symposium by giving delegates a 100 thousand welcomes to Dublin. Drs. Vermeulen and Bedlack presented at the joint opening session to give first hand insights on why studying both ALS/MND environmental risk factors and alternative treatments are so vital to ALS research.

During the opening plenary session I provided a brief overview of the work of the International Alliance and announced the recipients of the International Alliance Awards.

The recipients of the 2016 Humanitarian Award were James Allen Heywood and Benjamin Heywood. When their brother was diagnosed with ALS at the age of 29, Jamie and Ben were devastated at his prognosis and at the lack of effective treatments for the disease. They took up these challenges as a family and, with family and friends, founded two organisations: one tasked with finding effective treatments for the condition, and the other to tackle social isolation and to collect anecdotal data on what drugs, interventions or supplements might make a difference to people with ALS/MND. Today, these organisations are known as ALS Therapy Development Institute and PatientsLikeMe. Both organisations have been instrumental in facilitating publications by staff and collaborators in prestigious journals such as the BMJ, Neurology and Nature and have been cited literally thousands of times in other peer-reviewed journals.

"Together we can make a difference"

The Forbes Norris Award, first presented in 1994, honours the memory of Dr. Forbes “Ted” Norris, a neurologist dedicated to helping people with ALS/MND. Dr Terry Heiman Patterson, last year’s Forbes Norris recipient, presented the Award to Dr. Mamede de Carvalho. Dr. de Carvalho is a Portuguese physician who has contributed enormously to the care, treatment and management of people with ALS/MND over the last 20 years. Above and beyond his work in Portugal, Dr. de Carvalho has been instrumental in helping investigators in Brazil and other South American countries establish care and research programs in ALS/MND. He is the founder and enthusiastic supporter of the Portuguese ALS Association, which provides assistance to people with ALS/MND. He is a fine example to investigators both in rich and developing countries as to what can be accomplished through dedication, hard work and enthusiasm.

"this award is good for my PALS. Portugal is a small country. ALS is not well recognized there. They deserve this prize."
The program was jam packed with 90 oral presentations, nearly 500 posters, a number of formal satellite meetings and lots of informal networking opportunities.

Click here to find out what was discussed during the three day symposium and read the MND Association research blog, delegate twitter posts, the peer to peer reports and view audio clips. Recent reports posted provide some good highlights of the Clinical sessions.

The MND Australia twitter feed @mndaustalia and #alssymp also provides highlights from the scientific and clinical sessions. For an overview of Hopeful Highlights from the ALS Association click here.

Scientific presentations highlighted advances in therapeutic drug discovery, clinical trials, imaging and cellular biomarkers and the review of clinical trials guidelines to streamline the process in the future.

The clinical sessions continue to grow highlighting the importance placed on improving care for people living with ALS/MND and their carers. Presentations covered a range of topics including diagnosis, eating and cognition, quality of life, mindfulness, NIV, using patient reported data in research through Patients Like Me, Telemonitoring for people living with MND, personalised prediction of survival tool and carer support.

Satellite Meetings
The fourth Pan Asian Consortium on the Research and Treatment of ALS/MND (PACTALS) meeting provided an update on progress with presentations from China, South Korea and Japan. The PACTALS website is now well established and progress is being made on the shared ALS/MND Registry. The next meeting will coincide with the WFN meeting in Kyoto in September.

This year’s Project MinE meeting was again very well attended and provided updates on progress and results to date. There are now 17 countries involved and 35% of DNA profiles have been collected. In total Project MinE has led to the discovery of 4 ALS genes so far. At the meeting researcher Rick van der Spek presented the Project MinE databrowser, where people can find (anonymous) project MinE data on several genes. This is a great way to share data with other researchers and with research of other diseases.

An overview of the meeting is available here.
Australian researchers funded by MNDRIA were well represented at the Symposium with 11 platform presentations, a number of posters one of which was the joint winner of the biomedical poster prize:

Just off the plane @whereisdaz taking questions following presentation on behalf of @jjyerbury #alssym #MND_RIA

Great talk on @MND_RIA funded research from Diane Moujalled #alssym

Farg (Australia): DNA damage response is induced by the C9ORF72 repeat expansion in ALS @MND_RIA #alssym

Looking forward to @MND_RIA Charcot Grant 2017 recipient @NgoShyuan talk on energy metabolism in #ALS #MND #alssym

Great talk: @NgoShyuan wraps up with significance for therapy and thanks for pw MND involved in study #alssym
Up next: Peter Crouch giving update on work to develop copper compound into potential therapeutic @MND_RIA #alssymp

Great pres from @MND_RIA funded N. Geevasinga: Orla Hardiman kicks off question time - 'Fantastic Study' #alssymp

Emma Devenney presenting work of @MND_RIA funded Rebekah Ahmed - Eating & Cognition: Effect on survival #alssymp

7 Australians presenting this morning! Up first @MND_RIA Beryl Bayley Post Doc fellow 2015-2017 P. Menon #alssymp
Congrats to @MND_RIA Beryl Bayley MND post doc fellow 2017-2019 Emma Devenney on a great presentation #alssymp

@MND_RIA funded researcher Ian Blair on CCNF mutations leading to UPS dysfunction - great collaboration #alssymp

@MND_RIA @Cure4MND funded Marco Morsch: Transfer of ALS protein aggregates between MN in zebrafish #alssymp

Congratulations to Albert Lee @Macquarie_Uni joint winner of the biomedical poster prize at #alssymp - well done!!!
Each day delegates were greeted by the International March of Faces banners that filled the foyer. These faces provided a stark reminder to delegates of the need to continue to work hard to accelerate research advances to give people living with ALS/MND across the globe real hope for an effective treatment in the not too distant future.

With record attendance at The Alliance Meeting and the Symposium, live streaming of the Ask the Experts globally, continued growth of the Allied Professionals Forum and the increase in special interest satellite meetings the Annual International Meetings once again inspired and motivated many.

All present agree that global collaboration is key to advancing research towards effective ALS/MND treatments and cures and the collaborative vibe at the conference was certainly infectious! Dr Chio from Italy ended his talk at the joint closing session ‘A precision medicine approach to ALS: What will it take?’ by saying to the audience “Go and collaborate to be most productive!”

The meeting wrapped up with an invitation from co-hosts Rob Goldstein (ALS TDI) and Sara Feldman (ALS Hope) to the 2017 International Meetings in Boston, USA, from 5th to 10th December 2017

Final words of hope are provided by Dr Brian Dickie the organiser and driver of the Annual International Symposium on ALS/MND.

Carol Birks National CEO MND Australia Chairwoman International Alliance of ALS/MND Associations
APPENDIX:

Links to Presentations

Alliance Meeting:
Opening Remarks from the GM: Year In Review – Rachel Patterson, General Manager
Beyond Awareness Gaps – Hiroki Okabe, Japan ALS Association
The Cost of Achieving Your Goals: Assistive Technology Program in Israel – Efrat Carmi, IsrALS
A Comprehensive Information and Education Resource for People with MND, their Carers, Health and Community Care Providers – Gina Svolos, MND Australia
New Challenges to Our Association – Alessandra Dorca, ALS Pro-Cura Association
ACELA: A Vision of Hope – Rocio Reyes, ACELA, Colombia
Life Is Now – Gudjon Sigurdsson, MND Iceland
A Phased Shift in MND Care in Scotland – Craig Stockton, MND Scotland
Victories and Partnerships – Tatiana Mesquita e Silva, ABrELA
Local Fundraising for Project MinE – Gorrit-Jan Blonk, ALS Netherlands
Using the MND Association’s Experience to Promote Optimal Care and Support in Russia – Anna Kassianova, Martha-Mary Medical Centre “Miloserdie”
The South African MND Caregiving Experience: Lessons Learned from a Cross-Country Collaboration – Melinda Kavanaugh, University of Wisconsin-Milwaukee
First Ever ALS Student Exchange – Jodi O’Donnell, Hope Loves Company
The ALS Analyzer Mobile App: Engaging PALS in the Development of New ALS Monitoring Tools – Idit Ron, Prize4Life
PULSE – Christine Tabuenca, ARSLA
Precision Medicine: How Can It Help Advance the Discovery of ALS Subtypes and Speed Drug Development? – Rob Goldstein, ALS Therapy Development Institute
Meeting the Research Communication Challenge: Our Experience – Sally Light, MND Association of England, Wales and N Ireland
Scientific Update – Dr. David Taylor, ALS Canada
ALS Investment Fund – Gorrit-Jan Blonk, ALS Foundation of the Netherlands
Keys to Strong, Transparent Governance – Andrea Pauls Backman, Les Turner ALS Foundation
2016 Strategic Planning Workshop: Outcomes (No video available, click to download presentation PDF)
Allied Professionals Forum (APF)

If you wish, you can browse all of the APF presentation videos at once on the Alliance’s 2016 APF YouTube Playlist.

About the International Alliance of ALS/MND Associations – Carol Birks

The ALS Assistive Technology Challenge: Winners – Lucie Brujin

Message Banking: Impact on Quality of Life of People with ALS/MND – Lesley Doyle

Message Banking vs. Voice Banking: A Very Successful Proactive Model for People with ALS/MND – John M. Costello (no video available, click to download presentation PDF)

The Development of a Voice Banking Volunteer – Louise Rickenbach

Cultivating Compassion: Caring for Families Living and Dying with ALS/MND – Ronald Hoffman

Adopting a New Way of Working to Support and Provide Information for Families Where a Parent/Guardian Has ALS/MND – Karen Welsenaer

The Carers’ Alert Thermometer (CAT): Identifying ALS/MND Carers’ Support Needs – Mary O’Brien

Well-Being and Care Burden of Close Relatives to Persons with ALS-FTD – Brigit J. Hovmand

What Do People Living with ALS/MND Think About Their Swallowing? – Dominika Lisiecka

The Clinical Utility of a Self-Reported Swallowing Outcome Measure – Laurie Sterling

First Contact Group: An Anticipatory Approach to Palliative Care – Colin Pearson

Withdrawal of Mechanical Ventilation at Patient Request in ALS/MND – Alison Armstrong

Mechanical Insufflation Exsufflation (M-IE) and Breath Stacking: The Patient’s Experience – Rachel McConnell

Eyedriveomatic – Karen Pearce

I Can Do It: The Impact of a One-Day Training Intervention on Occupational Therapist and Speech Pathologist Confidence in Working with Assistive Technology for Clients with ALS/MND – Kristina Dodds

How You Can Use 3D Printing in Your Practice – Kevin Caves