

The Annual International ALS/MND Meetings

Glasgow, December 2018

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. 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 of ALS/MND Associations annual meeting, an Ask the Experts session and the Allied Professionals Forum. In 2018 the meetings were held from the 4 to 9 December and hosted by Alliance member MND Scotland.

26th Meeting of the International Alliance of ALS/MND Associations



The Alliance meetings commenced on the morning of 4 December with the AGM where new directors from ALS Argentina and MND Iceland were elected to join the board. Calaneet Balas, CEO ALS Association, was elected Chairwoman and brings a wealth of knowledge and expertise to the role. At the AGM directors reported on the work of the Alliance during 2018 as well as new Alliance initiatives including the establishment of an Alliance **Scientific Advisory Council** and a **PALS/CALS Advisory Council**.

A jam packed Alliance Meeting program followed which included examples of support programs from around the world, advocacy and awareness raising initiatives, organisational development, partnerships, app development and more. Carol Birks, CEO MND Australia, presented on 10 years of advocating for an NDIS to meet the needs of people living with MND and Rod Harris, CEO MND Victoria, presented on influencing the voluntary assisted dying debate in Victoria. As always these presentations inspired and challenged us to think more broadly about our own organisations and the services we provide. Friendships were reignited and opportunities to learn from each other were presented in every conversation. The final presentation was a scientific update from Dr David Taylor, ALS Canada, who gave a fabulous overview of recent advances in research which is well **worth viewing**. The @mndaustralia, @CEBirks and @ALSMNDAlliance twitter feeds provide highlights from the Alliance Meeting and See **Appendix 1** to view all presentations.

It was very moving to be greeted each day by the International March of Faces banners including the 2018 banner featuring Australians Bill Hicks, Joanne Pratt and Dean Olsson from MND

Victoria. These faces provided a stark reminder to delegates of the need to continue to work hard to improve care and accelerate research to give people living with ALS/MND across the globe real hope for a better quality of life and an effective treatment in the not too distant future.

The meeting wrapped up with an invitation from MND Australia, David Ali and Carol Birks, to attend the International ALS/MND Meetings in Perth from 1 to 6 December 2019. There was much interest and enthusiasm for a sunny Alliance meeting in 2019

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. MND Scotland hosted the 2018 Ask the Experts in partnership with the International ALS/MND Alliance of ALS/MND Associations on Wednesday 5 December. The event was attended by an audience of people affected by MND from Scotland and around the world, who gathered to hear the latest research. Following the four presentations the audience asked the presenter's lots of questions, with many focused on clinical trials, at a lively Q and A session.

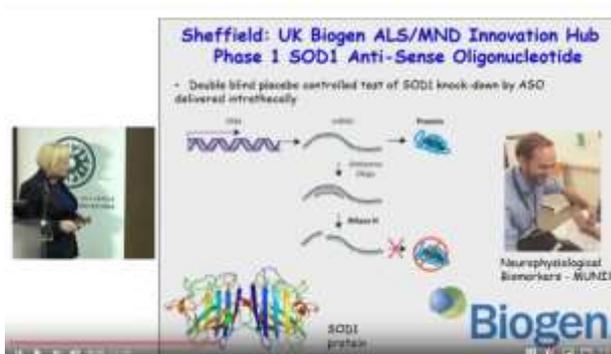
Each year the Ask the Experts event is live streamed on social media and recorded. A video of all the sessions can be viewed on [MND Scotland's YouTube channel](#). In addition the pdf of slides from each presentation can be viewed in the links below. The program provided a fascinating, easy to understand overview of the current research landscape and highlighted why this is a time of increasing optimism for the ALS/MND community.

Dr Brian Dickie, MND Association <<<

What Causes ALS/MND: Dr Brian Dickie, Director of Research at the MND Association of England, Wales and Northern Ireland, began the session with a talk on the potential causes and contributory factors to the development of MND. Dr Dickie covered genetics, Project MinE, pre-implantation genetic diagnosis and the implications of discovering more genetic mutations implicated in MND.



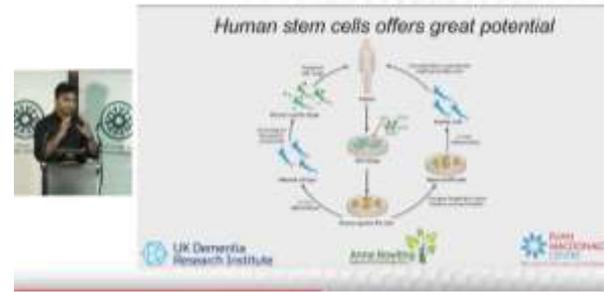
Professor Dame Pamela Shaw, Sheffield University <<<



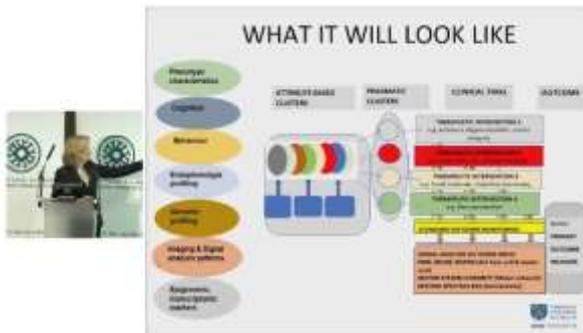
Current Key Developments in MND Research and Looking to the Future: Professor Dame Pamela Shaw spoke on the topic of current key developments in MND research and looking towards the future. Professor Shaw covered the complexity of MND and why developing treatments is so challenging, the multiple mechanisms that contribute to MND, precision medicine, gene therapy development and advances and innovations in symptom management to improve the lives of people living with ALS/MND

Dr Bhuvaneish Selvaraj & Dr Arpan Mehta, Euan MacDonald Centre <<<

Stem Cells in motor neurone disease: The team from the Euan MacDonald centre spoke on the importance of using stem cells in MND research. Drs Selvaraj and Mehta covered stem cell technology, the importance of patient derived stem cells in accelerating research and the potential of high throughput drug screening in accelerating the search for effective therapies.



Professor Orla Hardiman, Director of the National ALS Clinic & Irish ALS Research Group <<<



Clinical Trial in ALS, Time for Optimism: Professor Orla Hardiman spoke on the topic of clinical trials in MND and why it is a time for optimism in MND research. Professor Hardiman covered the increasing number of drug compounds under development, the potential to re-purpose existing drugs through investigator led trials such as The Lighthouse Trial, development of biomarkers and the future of trial design in selecting the right patient, right drug, right

dose at the right time (**personalised prediction model in the future**).

16th 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 on models of support for people living with MND, carers and children, cannabis, cough and dysphagia, sexuality, respiratory care, music therapy and more.



The Allied Health Professional Award was inaugurated in 2018 by the International Alliance of ALS/MND Associations to recognise an individual committed to providing exceptional care to people with ALS/MND. To celebrate the sharing of expertise and exploration of new ideas to improve patient care and to recognise significant contribution to the advancement of ALS/MND clinical management. The recipient of the 2018 Allied Health Professional Award was Sara Feldman a physiotherapist from the ALS Hope Foundation and a long time co-chair of the Allied Health Professionals Forum. Read more about Sara's work [here](#).

Colin Jones gave the **opening address** providing an inspiring insight into living with MND. Colin thanked the audience for the work they do and the value of multidisciplinary care in providing support and improving the quality of life of people living with MND and their families. He also highlighted the challenges relating to funding to ensure multidisciplinary teams have the resources they need to provide this support. *“Post diagnosis it is like facing a precipice, there is a lot of fear for the future and what you give to us takes some of that fear away and makes life worth living and gives us a degree of optimism and purpose, never forget that.....”*

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 initiate change to better meet the needs of the people living with ALS/MND that they care for. Of particular relevance and interest to the current Australian context was the talk from Judith Newton on the work to develop **Care – MND** a platform that integrates clinical care, audit, research and evaluation to provide ongoing comprehensive monitoring of every person living with MND in Scotland. See [Appendix 2](#) to view all presentations.

29th International Symposium on ALS/MND Symposium

The International Symposium is the largest medical and scientific conference on ALS/MND in the world. It is the premier event in the ALS/MND research calendar breaking records once again this year with over 1300 delegates demonstrating the energy and dynamism of the global ALS/MND research community.

Over the three-day event the concurrent scientific and clinical sessions covered biomedical research, diagnosis and prognosis, causes of ALS/MND, clinical trials and treatments and improving well-being and quality of life and more. For abstracts and summaries of these themes visit the MND Association [Symposium Live](#) website and abstracts available online – See [Appendix 3](#) .

The program was jam packed with oral presentations, poster sessions, a number of formal satellite meetings and lots of informal networking opportunities



The opening address was given by her HRH The Princess Royal, Patron of both MND Scotland and the MND Association. At the morning tea break David Ali and Carol Birks, MND Australia, were honoured to be invited to a special reception to meet the Princess Royal.

Each year during the opening session the International Alliance of ALS/MND Associations presents two awards.

The **Forbes Norris Award**, first presented in 1994, honours the memory of Dr. Forbes “Ted” Norris (1928-1993), a neurologist who dedicated his career to helping people with ALS/MND. The purpose of this prestigious 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 the disease. The recipient of the 2018 Forbes Norris Award was Dr Angela Genge. Director – ALS Clinic & Director – Clinical Research Unit, Montreal Neurological Institute & Hospital. [Read more about her work](#)

The **Humanitarian Award** was inaugurated in 2000 by the International Alliance of ALS/MND Associations to recognise a non-scientific contribution to the fight against ALS/MND. The Humanitarian Award is intended to recognise and encourage individuals and/or groups whose

work makes, or has made, a contribution of international significance for people affected by ALS/MND. The recipient of the 2018 Humanitarian Award was Dr Brian Dickie, Director of Research at the MND Association. Dr Brian Dickie has played a lead role in the world community of ALS/MND people for 22 years. Under his leadership the International ALS/MND Symposium has grown to become the preeminent ALS/MND meeting attracting over 1000 delegates from around the world each year. [Read more about his work.....](#)

The annual Paulo Gontijo Prize in Medicine is presented to an outstanding young investigator working on ALS/MND. Named after the founder of the Brazil-based institute, Mr Paulo Gontijo, the award recognises and encourages research into the disease by carefully considering recent scientific contribution that increased the understanding of MND. The 2018 winner of the PG Award is the UK-based researcher Dr Rickie Patani of University College London (UCL) for his paper published in Nature Communications in May 2018. This work demonstrated how improper functioning of RNA, a molecule implicated in the creation of proteins from our DNA, leads to degeneration of motor neurones. Read more about his work [here...](#)

Research presentations

The gap between basic science and clinical practice is decreasing as discovery continues to pave the way for potential treatments.

Research highlights from the Symposium included a major focus on clinical trials with associated dedicated sessions on clinical trials and trial design, tissue biomarkers, measurement of clinical progression and preclinical therapeutic strategies.



Debates centred on the question 'Is MND one disease or a group of different diseases?'

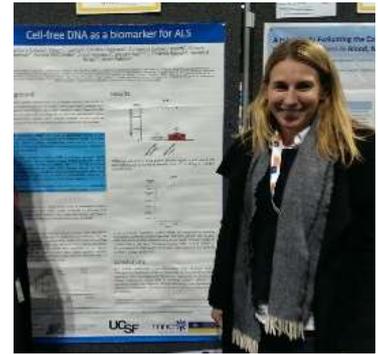
Multiple disease could explain lack of success in clinical trials where all sub-types are included. Popular outcome of debates favoured multiple small clinical trials with targeted groups in lieu of broad groups seeking statistical significance with larger numbers of patients enrolled.

Basic science continues to be the realm of discovery with sessions on cell biology and pathology; neuropathology; neurophysiology; axonal degeneration; genetics and genomics; non-neuronal cells; disease models; epidemiology

Clinical highlights included presentations on information, autonomy and decision making; technology and ALS; clinical support and quality of life; cognitive and psychological change; end of life decisions.

For detailed highlights check out MND Association [research blogs](#):

Once again, the Australian contingent of researchers made their mark and the MND Research Institute of Australia (MNDRIA) is proud to have funded many of those presenting. The Symposium provides the perfect opportunity for engagement with international research directors and managers and liaison with expat Australian postdoctoral scientists and the many Australian researchers who were present. We were all enormously proud of the strong Australian presence at the Symposium and the big part MNDRIA has played in making this happen.



Poster session - The Aussies were also out in force for the poster session. Congratulations to Dr Fleur Garton from the University of QLD for runner up for the scientific poster prize. David Ali, Carol Birks and Janet Nash took advantage of the Poster Sessions to promote Perth distributing clip on Koala's to all present and inviting them to return the Koala to Perth next December!

Check out some of the **posters and slides** uploaded by presenters to the MND Association 29th International Symposium website, see [Appendix 3](#), and check out twitter @mndaustralia @MND_RIA @CEBirks #alssymp, for further insights and highlights.

Satellite Meetings

ENCALS (European Network to Cure ALS) meeting to discuss international collaborations and translation of new developments to the clinic. The highlight was Julian Gold's presentation of the phase I clinical trial of antiretrovirus treatment Triumeq: The Lighthouse Project. This has resulted in international centres in UK (Ammar al Chalabi), Chicago (Teepu Siddique) and Belgium (Leonard van den Berg) joining the Phase II trial to be led from Australia.

The Pan Asia Consortia for the Treatment of ALS/MND (PACTALS) met to discuss potential topics for study within the PACTALS structure; shared registries; current clinical trials within PACTALS; organisational structure for consideration by the key members and the two day Symposium to be hosted by the Japanese members in 2020.

Project MinE meeting was attended by Anjali Henders representing the SALSA team and results from Australia.

Cytokinetics Meeting: Announcement of new data from the Phase II Trial Fortitude-ALS using their drug Reldesemtiv. Read the announcement [here](#)

Biogen Trials: BIIB067 (SOD1) and BIIB078 (C9orf72) antisense oligonucleotide treatment to knock down the gene toxicity. Only for gene +ve carriers. Multiple sites in US and Europe but not Australia.

Neale Daniher and the late Ian Davis were winners of the prize4life Shay Rishoni Patient Impact Award 2018. This annual award recognises and rewards ALS/MND patients whose activities have made significant and outstanding contributions to ALS/MND research and drug discovery efforts.

The meeting wrapped up with an invitation from David Ali, President MND Australia, to attend the International ALS/MND Meetings in Perth from 1 to 6 December 2019. MND Australia, in partnership with the MND Association of WA, is proud to host the International meetings in 2019 at the Perth Convention Centre this December:

- 2 December - Ask the Experts
- 3 December - Allied Professional Forum
- 4 – 6 December 30th International Symposium on ALS/MND

We hope you can make it!

Carol Birks, CEO MND Australia

Janet Nash, Acting Executive Director Research, MND Australia

APPENDIX 1:

26th International Alliance of ALS/MND Associations Annual Meeting

Presentations on Advocacy:

1. **Introducing An Advocacy Service – Roslyn Scholarios MND Scotland**
2. **10 Years of NDIS Influencing – Carol Birks MND Australia**
3. **The United States National ALS Register – Paul Mehta**
4. **ALS Centers – Christine Tabuenca – ARSLA**
5. **Influencing and Voluntary Assisted Dying – Rod Harris MND Victoria – Notes**
6. **From Side of Desk to Front of Mind – Tammy Moore ALS Canada**

Presentations on Programming for PALS/CALS:

1. **Craig Stockton – Creating Educational Videos**
2. **Online Support – Efrat Carmi – Israel Association**
3. **Challenges in India for Caregivers of Patients – Ajay Gupta Asha Ek Hope Foundation of MND/ALS**
4. **Project Revoice – Brian Frederick**
5. **The Diversified services and awareness campaigns of ALS Liga Belgium – Lisa Castro**
6. **Introduction of communication support activities in Japan – Katsushi Tamaki**

Presentations on Organisational Development:

1. **Nina Levitskaya Russian Charity, Advances after the 10th Anniversary – Gleb Levisky**
2. **A cause for all – Adriana Oda**

Presentations on Partnerships:

1. **Together we're Strong! – The Dutch approach – Theo Meister**
2. **Project 'ANDAR' – Pablo Aquino/Dario Ryba**

Presentations on Stakeholder Engagement:

1. **Improving MND Care Survey – Nick Goldup**

Presentations on Looking to the Future:

1. **Blink to Speak – Geet Rathi**

Scientific Update Presentation: Dr David Taylor – [Watch here](#)

APPENDIX 2:

16th Allied Professionals Forum (APF)

Welcome Address - Colin Jones, A personal perspective of living with MND

Access to recordings of the following presentations and powerpoints are available [here](#)

Session One:

1. Judith Newton, Scotland: Care MND - Clinical Audit Research Evaluation
2. Emily Richardson, England: One size does not fit all – MND Association - expanding information resource formats
3. Adele O’Toole, England, History and development of the MND Association MND Connect Helpline
4. Marjolein Cleaver, England: Hospice Volunteers supporting those with ALS/MND and cognitive change

Session Two:

5. Dianne Fraser, UK: Gordon Aikman Scholarship Award, Breath Stacking Interim Results and Learning Strategies
6. Charlotte Massey, UK: Challenges of assessment and management of cough augmentation in ALS/MND
7. Jodi Allen, UK: Multidisciplinary assessment and management of cough for airway clearance
8. Dominika Lisiecka, Ireland: How dysphagia changes the perception of food in ALS/MND- the perspectives of people with ALS/MND and their caregivers

Session Three:

9. Christian Lunetta, Italy: Advanced care planning in ALS/MND patients
10. Dr Rachel Tams, England: What do Children need when a parent has ALS/MND?
11. Jane Martin, England: Non-invasive ventilation from diagnosis to end of life, Hospice staff training in discussions, decisions and practical management
12. Wendy Bennett, England: ‘A time to remember’ A practical framework to support families who have been bereaved

Session Four:

13. Sandra de Morre, Netherlands: Sexuality in ALS, breaking the conspiracy of silence
14. Alisa Apreleva, Russia: Music therapy in multidisciplinary ALS/MND rehabilitation
15. Viviana Faierman, Argentina: Art therapy for people with ALS/MND
16. Gill Craig, UK: Use of Cannabis extract spray

APPENDIX 3:

29th International Symposium on ALS/MND

1. **Symposium overview:**
<https://www.mndassociation.org/symposium/symposium-live/>
2. **Forbes Norris award:** <https://www.alsmndalliance.org/meetings/awards/>
3. **Humanitarian award:** <https://www.alsmndalliance.org/meetings/awards/>
4. **Paulo Gontijo Prize in Medicine:**
<https://www.mndassociation.org/news-and-events/latest-news/dr-rickie-patani-wins-the-paulo-gontijo-award/>
5. **Platform Presentation Abstracts – download pdf to view**
<https://www.tandfonline.com/doi/abs/10.1080/21678421.2018.1510202>
6. **Poster Presentation Abstracts – link through to selected theme**
<https://www.tandfonline.com/toc/iafd20/19/sup1>
7. **ENCALS:** <https://www.encals.eu/meetings/encals-satellite-meeting-2018-glasgow/>
8. **PACTALS:** <http://pactals.org/wp-content/uploads/2018/12/Meeting-report-8th-PACTALS-meeting-2018.pdf>
9. **Project MinE:** <https://www.projectmine.com/status/>
10. **Cytokinetics:** <https://globenewswire.com/news-release/2018/12/10/1664283/0/en/Cytokinetics-Announces-New-Data-Presented-at-the-International-Symposium-on-ALS-MND.html>
11. **Biogen ALS ASO trials:** <https://alsnewstoday.com/ionis-sod1-rx-biib067/>
12. **Shay Rishoni Patient Impact Award:**
<https://www.facebook.com/FightMND/videos/shay-rishoni-patient-impact-award-thank-you-speech/208539046744238/>