



In this edition

My Aged Care when English is not your first language... National Carers Week 2017... Christmas puppies... New publication from ALS Quest... MND NSW achieves NSW Disability Service Standards verification and accreditation... ALS/MND without Borders... and more

A Message from the CEO

Our Walks to d'Feet MND have been very well supported during 2017. If you get in fast you can still register for the Walk to d'Feet MND Wagga Wagga to be held on 15 October. Our Sydney Walk to d'Feet MND, which is on Sunday 5 November, is the 10th Anniversary of this event. Come along and celebrate this milestone! You can find registration links inside this edition of *e-news* or at mndnsw.asn.au.

Congratulations to Gujarati Brahman Samaj of NSW Inc., the organisers of this year's Navratri 2017 Garba Dance held on Saturday 23 September at Kellyville benefitting MND NSW. Our MND NSW Ambassador, Ben Gooley, is pictured above (third from right) at the event. Read more on page 9.

On the advocacy front, we are continuing our discussions with the Department of Health and Aged Care in Canberra about the entry process for My Aged Care (MAC) for people 65 years and older with MND. If you haven't let your MND Advisor know about any difficulties you might have had with entry into MAC, please let your MND Advisor know.

Graham Opie



Gundaroo Music Festival

If you haven't attended a Gundaroo Music Festival don't miss this year's event on Saturday 14 October 2017. [You can get your tickets online here.](#)

The Goulburn Toyota Gundaroo Music Festival is the vision of a very talented musician Scott Windsor who died from MND in April 2015. [Watch the video of Scott's wife, Sue,](#) talking about how the festival helps and what it means to her family.



Living Well with MND Information Day 17 October at Wollongong

Living Well with MND is an informative day for people living with motor neurone disease, their families and friends.

You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

There is no cost to attend but you need to reserve your place. [Find out more about Living Well with MND Information Day here.](#)



Register now Walk to d'Feet MND 15 October - Wagga Wagga

Don't forget early bird registrations for our Wagga Wagga Walk to d'Feet MND on Sunday 15 October are closing on 8 October. [Register today here!](#)



My Aged Care when English is not your first language

My Aged Care is the entry point to all services for people aged 65 years and older in Australia.

My Aged Care can provide you with information about the services offered by the Australian Government that can give you the extra help you need around your home. These services include domestic assistance, personal care, meal services and nursing care.

如何进行评估 (How assessment works)
CAT 评估 (ACAT assessments)
家庭援助评估 (Home Support Assessment)
家庭协助 (Help at home)
家庭护理服务组合 (Home Care Packages)
费用说明 (Costs explained)
养老服务投诉计划 (Aged Care Complaints Scheme)
服务章程 (Service charter)

Help at home services are delivered in two ways: through the Commonwealth Home Support Programme and through Home Care Packages.

Many of the information resources from My Aged Care are provided in languages other than English. Select your language and [see the resources available at the My Aged Care website.](#)

Introducing new staff...

Ana Petrovic | MND Advisor

Hello! I have recently joined the team at MND NSW as MND Advisor for South-West Sydney, Illawarra and Shoalhaven areas. My background knowledge and experience comes from working in rehabilitation. I am an exercise physiologist, but I have also completed a Graduate Diploma in Psychology. I am looking forward to getting to know members and their families as well as working with the MND NSW team and liaising with service providers.

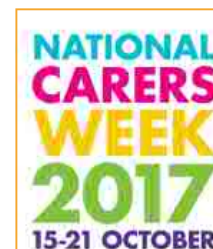


Member library

Don't forget that members and carers have the opportunity to borrow MND-related books and DVDs for up to a month at a time, at no cost, from our member library. Contact the MND Info Line ph. 02 8877 0999 or email info@mnidnsw.asn.au for details.

Come along and celebrate National Carers Week!

We are hosting an informal morning tea at the MND NSW Centre at Gladesville for current and former carers of someone with MND on Wednesday 18 October. We would love to see you there. [More info here.](#)



Sun Sense

A huge thank you to Sun Sense who have come on board as a sponsor for all of our Walks to d'Feet MND. At our next Walk, make sure you drop by the merchandise table to get some sunblock on.



Talk-Link MND Carer Wellbeing Program by telephone

Carers NSW and Motor Neurone Disease Association of NSW have partnered to offer the Talk-Link program to residents of NSW providing care to someone with MND. Talk-Link is a six-week telephone program for adult carers commencing Tuesday 24 October, facilitated by professional counsellors. There is no charge to register. For more information or to register contact Carers NSW Carer Line ph. 1800 242 636.



For Sale

Mercedes Vito, reg. to March 2018. 135,000km. Clean and serviced regularly. Seats six people including person in wheelchair and driver. Easy to drive and park, automatic, sliding doors on both sides, high head height. Built-in safety attachments on van floor to secure wheelchair. Easy remote control lift operation to lower platform to ground level. Bought for \$27,950 in 2017. Will sell for \$22,500. Contact Amber, Bulli NSW, ph. 0414 682 409.



Don't miss out...

Have a look at our new Christmas puppy. They are very cute. We only have a limited supply, so be quick. [Visit our online shop to order.](#)





SAVE THE DATE

Sunday November

5

Come along and help us celebrate
our 10th anniversary Sydney walk.
It's going to be a great day.

REGISTER

Walk to d'Feet MND

The name of this event reflects the hope and inspiration these special days provide for the MND Community. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with MND. You can create your own online fundraising page to raise funds in an individual name or a team name.

15
Oct

Walk to d'Feet MND Wagga Wagga

Apex Park

Register now

Supported by



Les Gray Plumbing



5
Nov

Walk to d'Feet MND Sydney

Blaxland Riverside Park, Olympic Park, Homebush

Register now

Supported by



Walk to d'Feet MND Port Macquarie

17 September, Westport Park

What a great morning in Port Macquarie for the Walk to d'Feet MND held on Sunday 17 September.

Thank you to the Port Macquarie pipe band who led off this year's walk.

What a great way to start the Walk. A big

thank you to everyone who came to our Walk this year and to our sponsors. Your support is greatly appreciated. [Click here to view more great photos from this year's event taken by Port News.](#)



Supported by

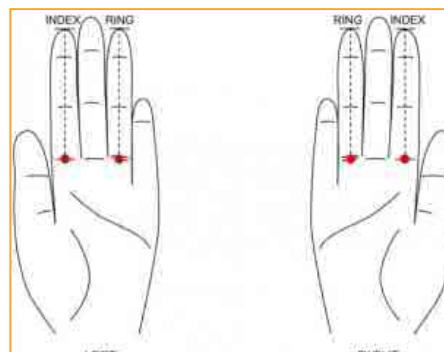


Laing+Simmons
Port Macquarie

New publication from ALS Quest

The first article of results from ALS Quest has been published! ALS Quest is looking for risk factors that might precipitate MND and participants (with or without MND) complete an online anonymous questionnaire.

The first set of data analysis has looked at the ratio of the length of the index finger to the ring finger and incidence of MND. For this first set of data, the researchers focused on this ratio and its potential to indicate risk of getting MND. A previous study (by other researchers) reported a lower mean ratio in patients with ALS compared with controls. To see if the results of this study could be validated with a larger number of subjects, ALS Quest data was used. The ALS data does not indicate a link between MND and the ratio. [You can read the full paper here](#) or [find out more about ALS Quest here](#).



Videos online from ENCALS Meeting 2017

The European Network to Cure ALS (ENCALS) is a network of ALS/MND centres in Europe. The ENCALS Meeting 2017 was held in Slovenia and [free online videos](#) of the international researchers and clinicians presenting advances in research and clinical care are now available. Speakers include Prof Jernej Ule (UK), Dr Federica Agosta (Italy), Dr Russell McLaughlin (Ireland), Dr Thomas Bak (UK), Dr Janine Kirby (UK) and Prof Olivier Hermine (France).

Baking a difference

A very big thank you to Anjelica Karagiannis and her team of bakers who recently held a cake stall at Bunnings Kingsgrove. The final total raised was \$1154.10 which broke the sales record for cake stalls held at Bunnings Kingsgrove to date. Congratulations Anjelica!





MND CONNECT 2017: Register now!

Connecting people impacted by MND with Australia's leading MND researchers

Saturday 11 November, University of Sydney
www.mndaustralia.org.au/MNDConnect



Do you want to know what's new in MND research, current clinical trials and effective treatments for MND? Reserve your place at MND Connect, an interactive forum connecting people impacted by MND, with Australia's leading MND researchers. In 2017 this Forum will be held at the University of Sydney. People with a disability and their carers may reserve a disabled parking spot at the venue, or receive a wheelchair taxi voucher or subsidised travel from a regional area to attend this event. [Find out more about MND Connect 2017 here.](#)

Five Senses Twilight Market

Thank you to Ali Cooke of A La Mode Events who organised the very successful Five Senses Twilight Market in Lambton Park, with MND NSW as the chosen benefiting charity. Our thanks also to Louise Evans and her family who volunteered at the markets selling raffle tickets and MND NSW merchandise. A fantastic \$2,000 was raised.

MND Australia Research Update September 2017

This research update is produced by the MND Research Institute of Australia - the research arm of MND Australia. [Read the latest MND research news.](#)

Ron Kain Memorial Shield

Thank you and congratulations to the Campbelltown City Kangaroos RLFC who raised \$3,000 for MND NSW from their annual Ron Kain Memorial Shield game against the Picton Magpies. The Campbelltown City Kangaroos 1981 replica jerseys (pictured) were worn for the fixture. This year's game was held in honour of a Kangaroo and Magpie legend who died from MND in 2016.



Calling all chilli lovers

Don't miss the amazing Illawarra Chilli, Spice and All Things Nice Festival at Black Beach Kiama on Sunday 12 November, a fundraiser for MND NSW. Food, music and more than 60 stalls. An event for the whole family.



Navratri 2017 Garba Dance

Over 2,000 people attended this year's Navratri 2017 Garba Dance on Saturday 23 September at Kellyville organised by Gujarati Brahman Samaj of NSW Inc. The Navratri Garba is an Indian cultural dance that is a spectacle of colour with spiritual significance that celebrates the Mother Goddess, the Universal Mother, showering her love and affection on all humans.



MND Ambassador Ben Gooley attended and spoke about the work of MND NSW and the amazing support received from the organisers. Also amongst the invited guests were Alex Hawke MP, a friend and supporter of MND Australia, Dr Geoff Lee, MP for Parramatta and Dr Michelle Byrne, Mayor, The Hills Shire Council. The night was a spectacular success raising not only awareness about MND but also over \$19,000 to support people living with MND and MND research.

MND NSW achieves NSW Disability Service Standards verification and accreditation

In July 2017 MND NSW achieved verification under the NSW Disability Support Standards and accreditation under the QIC Health and Community Services Standards. We



undertake accreditation every three years and it requires two external assessors taking three days to review our policies, procedures, systems and work processes. The assessors also interviewed people with MND, carers, health professionals, MND NSW staff and board members.

Accreditation by a third party is important as it ensures that MND NSW support services are person centred and we are delivering services that are needed. In the overall summary the external assessors commented:

MND NSW's support services are predicated on person centred principles that recognise family autonomy, independence and decision making enabling people with MND to choose the level and nature of support and involvement with the organisation. The organisation is highly respected for its work with people living with MND, their families and carers, which is undertaken with understanding and compassion by the committed management and staff. There is strong leadership shown from the Board, Executive, and the senior management team in carrying out the organisation's mission and serving the community.

The Assessment Team were impressed by the high level of staff commitment to client outcomes, their collaborative approach internally and externally and the organisational culture of positive and supportive teamwork across all levels and roles in the organisation. The Board provide strong governance and are supported by systems that assist them in carrying out their responsibilities.

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The health services sector is undergoing significant change and MND NSW is in the midst of strategic growth opportunities and the governance and management challenges that may occur as a result.

This report offers a range of recommendations to assist the organisation to continue to improve and protect its capacity to demonstrate its effectiveness in meeting community needs and advocating on behalf of its consumers.

Thank you to members, families and carers, health professionals, MND NSW staff, MND NSW board members and the assessors for their valuable participation in this process.

Pudding time

Thanks to the amazing team at Pudding Lane, we are able to again offer our supporters the opportunity to purchase a Pudding Lane pudding at the very special rate of \$34.95 with 100% of money raised from these sales supporting people living with MND. Stocks are limited at this price, so be quick and treat yourself to the best Christmas pudding around.



Disability Advocacy Finder

Under the National Disability Advocacy Program the Australian Government funds agencies across Australia to provide people with disability access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.

Find out more about National Disability Advocacy Program by [watching the video here](#) or [click here to access the online Disability Advocacy Finder](#).



Upcoming Support Service events

Click to find out more.

10
Oct

Information Evening for people recently diagnosed with MND
Gladesville

17
Oct

Living Well with MND
Wollongong

18
Oct

Celebrating Carers Week – morning tea for current and former MND Carers
Gladesville

24
Oct

Talk-Link Carer Wellbeing Program by telephone
Six-week telephone program for adult carers, facilitated by professional counsellors

2
Nov

Link and Learn
A residential educational workshop held over two days and one night for carers
Cowra

11
Nov

MND Connect 2017
Community, researchers and clinicians in an interactive forum to discuss MND research
University of Sydney

25
Nov

Members' Christmas Party
West Ryde

5
Dec

Information Evening for people recently diagnosed with MND
Gladesville

MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other. [Find out more, including locations and dates, here.](#)

Your say about NDIS for young people aged 18-29 with a disability

Researchers at Western Sydney University want to hear the views of young people aged 18-29 with disabilities, their families/informal carers and disability service providers about their experiences during this time of life, and particularly during the transition to the National Disability Insurance Scheme. For more information contact Nicole Sharp ph. 4620 3755 at Western Sydney University or email n.sharp@westernsydney.edu.au. This study has been approved by the Western Sydney University Human Research Ethics Committee approval number H11784.



Ho Ho Ho

You, your family and friends are invited to the MND NSW Members' Christmas Party on Saturday 25 November 2017 from 2.30pm to 4.30pm at West Ryde.



Join us for an informal gathering. Renew old acquaintances, make new friends and meet MND NSW staff and board members. Afternoon tea and refreshments will be provided. Santa is expected to visit the children, so please let us know the ages of yours.

The venue is accessible with facilities to meet all members' needs. For assistance with travel arrangements, contact your MND Advisor. There is no charge to attend this event. For catering purposes, please confirm your attendance by 22 November 2017 by email to reg@mndnsw.asn.au or ph. 02 8877 0999 or 1800 777 175. Please let us know if you have special dietary requirements. We look forward to seeing you there!

Upcoming community fundraising events

Click to find out more.

7
Oct

MND Awareness Trivia Night
Cooma Ex-Services Club, Cooma

14
Oct

Gundaroo Music Festival
Gundaroo Park



3-5
Nov

Newcastle Italian Film Festival
Tower Cinemas Newcastle

12
Nov

The Illawarra Chilli, Spice and All Things Nice Festival
Black Beach, Kiama



17
Nov

Maria's Open Garden
Wanniassa, ACT

25
Nov

Craft Market Greystanes
Greystanes



BINGO with BALLS - 7.30pm every Tuesday night at STONEWALL
175 Oxford Street, Darlinghurst. Charity donation to MND NSW.

Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research?

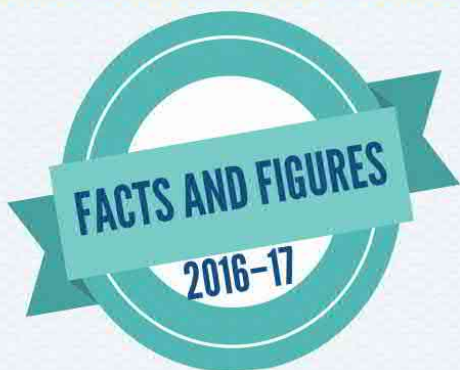
See here for how you can get started.

Get your Spring Package today

Look at this great value Spring Package. An MND T-shirt plus hat and socks.

Choose from a bucket hat or baseball cap plus ladies or mens socks when ordering. Package price is only \$35. Order yours today.





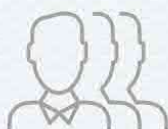
State MND Associations provide support and services to enable people impacted by motor neurone disease to live better for longer

UNTIL THERE IS A CURE, THERE IS CARE

* statistics as of 30 June 2017

1402

People living with MND in Australia are members of a State MND Association



654

People diagnosed with MND in the last year and their families supported by a State MND Association



44

Total number of MND Support Service staff

266

Education sessions delivered



33

Support groups

4160

People attended an education session

>43,000

Total visits, phone calls and emails to support people impacted by MND



578

Volunteers

4460

Information packs



4324

Assistive technology/equipment items supplied for short-term use



Freecall your State MND Association 1800 777 175

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ALS/MND without Borders

*The Pan-Asian Consortium for Treatment and Research in ALS (PACTALS) is the Asia-Pacific network of researchers and clinicians working with ALS/MND, established in December 2014. Chairwoman of the International Alliance of ALS/MND Associations and CEO of MND Australia, **Carol Birks**, recently travelled to attend several Asia-Pacific meetings.*

Over the last two weeks I have been privileged to experience different cultures and approaches to ALS/MND care and support. Differences underpinned by a common passion and commitment to improve the lives of people living with this devastating disease and their families.

7 to 9 September 2017

My travels started in Yangon, Myanmar. Following a conversation with Professor Nortina Shahrizaila about growing membership of PACTALS we agreed to approach Professor Win Min Thit who had attended the 2016 PACTALS meeting in Kuala Lumpur to suggest an MND workshop in Yangon. The suggestion was taken up with great enthusiasm by Professor Win and her team with an invitation for us both to speak at an MND Workshop. Due to distance I arrived a couple of days prior to the scheduled workshop and took the opportunity to meet with patients, family members and health providers to talk about the impact of MND on the family, day to day challenges and models of support. The aim of the meeting was to provide some tips and tricks to help make day to day care at home a bit easier and to open up a discussion on setting up a support group appropriate to local circumstances and culture. I was delighted and humbled to meet the families and to have the opportunity to hear their stories.

The next day I met up with Nortina at Yangon General Hospital. Nortina is a neurologist from Malaysia who has been instrumental in the establishment of MND Malaysia and PACTALS. Over lunch with our hosts Professor Win Mit Thit, Dr Ohnmar and their team of dedicated Neurologists and Palliative Care physician Dr Wah Wah Myint Zu, I

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learnt more about the healthcare system in Myanmar and the treatment available to people living with ALS/MND. Most of their MND patients were from rural communities who would come to Yangon for diagnosis but return to their communities to care for their family member at home. Palliative care services are currently focussed on cancer, but Dr Wah was keen to change this.

The workshop that afternoon was very well attended and commenced with an overview of MND from Professor Win Mit Thit. Nortina discussed MND Mimics, current guidelines for the management of ALS/MND and PACTALS. I provided an overview of the work of The Alliance and MND Associations in Australia. I also presented an introduction to advocacy and strategies for raising awareness with the aim of initiating discussion on existing resources and activities that could be translated locally.

The workshop concluded with an overview of Palliative Care in Myanmar from Dr Wah Wah Myint Zu who expressed interest in working collaboratively with the neurology team to develop a neuro-palliative model of support for people with MND in Myanmar.

First steps have already been taken thanks to the energetic and passionate Dr Ohnmar who, prior to our visit, had overseen the development and printing of the first MND information leaflet for patients. Professor Win Mit Thit will attend the PACTALS meeting in Kyoto this week with the aim of adding Myanmar to the PACTALS shared registry in the near future. Dr Ohnmar has been invited to join the Alliance as an individual Associate and we look forward to welcoming Myanmar to the International Alliance in the near future. I am very grateful for the invitation to visit this amazing country, if only very briefly, and for the kindness and hospitality of the Neurology team at Yangon General Hospital. A special thanks to Dr Khine Yee Mon for taking me to visit the market and the amazing Pagoda!

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10 to 17 September

Next stop Israel! The International Alliance of ALS/MND Associations offers members access to many resources and opportunities to help grow and develop the services and support they provide to people with ALS/MND. Not least of these opportunities are partnerships and friendship.

Out of a casual conversation with Sally Light, CEO MND Association England, Wales and Northern Ireland, grew a wonderful opportunity to visit our friend and colleague Efrat Carmi, CEO, MND Israel. We will be eternally grateful to Efrat and the ALS Israel board for the invitation to visit Israel and for being such amazing and generous hosts.

ALS Israel staff

ALS Israel is a small organisation employing four social workers who provide support and information to people diagnosed with ALS/MND across Israel.

Their focus is on a program of home visits for people recently diagnosed and the provision of ongoing support and information to ensure access to government support and services. A new program has been established as a result of sustained government lobbying to fund AAC for people with ALS. Specialist OTs are now employed to assess the communication needs of people with ALS who are then able to access the communication equipment they need funded by the Israeli Government.

We learnt that around 70% of people with ALS/MND in Israel choose to be ventilated which is in stark contrast to the UK and Australian experience. People are not able to discontinue ventilation once started leading to a high number of people living longer with extreme disability. Access to communication technology has therefore made a huge difference to the ALS population in Israel. This was a lively meeting with a fabulous team where we shared experiences and models of support.

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Brainstorm

We then visited the offices of Brainstorm, the Israeli based research and development group founded in 2004 that is pioneering autologous stem cell therapy for ALS.

They reported on the phase three trials about to start in the US. 200 patients from six centres in the US will take part in the double blind placebo controlled trial supported by a US grant. Stem cells will be collected from the participants bone marrow treated and then administered via an intrathecal injection.

Recruitment has just commenced and the final report is due in two years' time. Trials to date have confirmed safety and indicated a slowing of disease process.

Prize for Life

The visit to Israel provided the opportunity to meet with another Alliance member – Prize for Life – to learn more about their organisation.

We discussed the history of Prize for Life and their programs which include the ALS Analyser, ALS Research Forum, ProACT and the Shay Rizoni Prize. Future initiatives include the 2018 Genetic Challenge and a Hackathon in Boston at MIT in collaboration with the ALS Association. The Hackathon will throw open an IT challenge to students to work with ALS patients to develop assistive technology solutions.

Kadimastem

The research team at Kadimastem are working with Induced Pluripotent Stem Cells (IPS) to treat ALS. They have developed AstroRx – clinical grade astrocytes derived from human embryonic stem cells - which has shown to delay onset and prolong survival in SOD 1 mice. A phase 1/11a open label dose escalating clinical study of 21 patients is planned to commence soon in Israel.

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Dinner that night with Professor Mark Gotkine from the Department of Neurology at the MND Clinic in Jerusalem provided an opportunity to discuss the clinical management of MND in Israel. We learnt that medical Marijuana is commonly prescribed to address symptoms such as saliva, loss of appetite, fatigue and anxiety. The challenges and opportunities related to provision of services to the Arab population were also discussed.

Jerusalem

Of course a visit to Israel would not be complete without a tour of Jerusalem, Masada and the Dead Sea. We are grateful to ALS Israel for organising a fabulous tour provided by the wonderful Dani Margolis. Israel is a complex society with a rich and varied history and we certainly came away from the tour with a greater understanding and a keen interest in learning more.

Northern Israel

On our final day we travelled north to meet the ALS Israel Arab social worker, Badran, who was employed to support Israeli Arabs. Just 4 years ago ALS Israel was in touch with only 10 Arab people with ALS. Based on population it was estimated that there should be at least 70 people at any one time from the Arab community with a diagnosis of ALS. Badran was employed to reach out to the Arab community and to provide culturally appropriate support. He made contact with the local Arab neurologists and health sectors to inform them of the service and to link with ALS patients. Visiting local communities and families led to an increased understanding of the support available and contact with more people with ALS. Badran is now in contact with 65 people from the Arab community in Israel with a diagnosis of ALS and all people newly diagnosed are referred to Badran. Hebrew information has been translated into Arabic, an Arab Assistive Technology OT has joined the team and an Arab speaking clinic has been set up. The inaugural ALS Workshop will be held this month and a new project involving home

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visits from the palliative care doctor is due to start soon.

It is evident that this project has made a huge difference to the lives of many people in Israel with one Arab family reporting that it was as though their father had been resurrected following the involvement of ALS Israel and the provision of assistive technology to support communication.

For me this project encapsulated the drive, passion and commitment of Efrat and her team to fill gaps and improve the quality of life of people with ALS in Israel. It also provided the opportunity to experience Arab hospitality and delicious food – with thanks to Badran and his wife!

Eyecontrol

Our final night afforded the opportunity to meet with the eyecontrol team and be introduced to their innovative communication device. This device enables people to communicate and control their environment using a pair of glasses without the need to be at their computer or tablet. I look forward to hearing their presentation at the APF this year in Boston.

I am very grateful for the opportunity to visit Israel and learn first-hand about the work of ALS Israel. The main take home lessons from this visit were:

1. The success of the Arab sector project
2. The impact of ventilation for ALS patients and increasing communication needs
3. The advocacy work undertaken to get the AAC basket funded by the government and the difference that has made to people with MND
4. Insights into leading edge research and technology .

I would like to extend my sincere thanks to Efrat and the ALS Israel board for putting together such an interesting program and for their time, generosity and commitment to collaborating internationally.

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23 and 24 September

Beijing, 2017 Asia Pacific ALS/MND Conference

In my final months as Chair of the International Alliance of ALS/MND Associations before stepping down at the AGM on 5 December it was an honour to be invited to present at the 2017 Asia Pacific ALS/MND Conference in Beijing on 23 and 24 September. Hosts Beijing Oriental Rain ALS Care Centre (ORACC), supported by many passionate volunteers and the MND Association of Taiwan, delivered a very successful meeting showcasing latest research and the work of ALS/MND associations in the region. Over 250 delegates including 66 people living with MND from 22 provinces in China attended the meeting which was also live streamed nationally. The President of ORACC Mrs Yuzhu Liu opened the meeting and invited me and the government representatives present to speak and launch the ORACC Status Quo report – the first report on ALS patients in China. The meeting and launch of the report attracted extensive media coverage in print and TV.

The first session focussed on people living with MND with passionate messages of hope from the founders of ORACC, Wang Jia, a person living with ALS and recorded messages from Gudjon Sigurdsson, President MND Iceland and Tom Qu, President MND Taiwan.

This was followed by presentations from ALS/MND Associations in the region including ALS/MND Alliance members, Taiwan MND Association, Mongolian ALS Association, MND Malaysia, Russian Charity ALS Foundation, Japan ALS Association, Beijing Oriental Rain ALS Care Centre and Shaanxi ALS Association and a newly formed group in Shanghai not yet linked with The Alliance. During this session I provided an overview of the MND care and research landscape in Australia, the Pan Asia Consortia for the Treatment of ALS (PACTALS) and the International Alliance of ALS/MND Associations.

Other sessions included presentations from clinicians, engineers and

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researchers talking about advances in research, ventilation and communication technology.

I am very grateful for the invitation to attend and present at the 2017 Asia Pacific ALS/MND Conference and for the kindness and hospitality of the ORACC team, the student volunteers and Kiki Qu. It was a great opportunity to meet with Alliance members from the region to learn more about the work they do to support people living with ALS/MND in their countries and to talk about the future direction of PACTALS and The Alliance. There was an immense feeling of love, compassion and commitment to improving the lives of people living with ALS/MND in the Asia Pacific no matter how small the organisations or how few resources available. Together in the worldwide fight against ALS/MND #ALSMNDwithoutborders.

Carol Birks

*Chairwoman International Alliance of ALS/MND Association
CEO, MND Australia*





Motor Neurone Disease Association of New South Wales

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(Locked Bag 5005, Gladesville NSW 1675)

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 <http://fb.me/mndnsw>

ABN 12 387 503 221

PATRON His Excellency General The Honourable David Hurley AC DSC (Ret'd),
Governor of New South Wales

VICE PATRONS Melinda Gainsford Taylor, Kevin Langdon OAM, The Hon. Mr.
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Sarah Bouch

Support Service Manager
Gina Svolos

Information Line Advisor
Mary Clifton

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Maguire

FlexEquip Coordinator
Maree Hibbert
FlexEquip Assistants
Youvanna Chantharasy,
Nicole Smith
FlexEquip Support Officer
Julie Becke

**Information Resources
Coordinator**
Penny Waterson

**MND Advisor
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Team Leader**
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**...and many valued
volunteers**