



### **In this edition**

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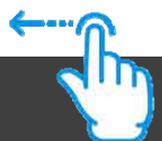
### **A Message from the CEO**

2018 is upon us and we're well into the year already.

This action packed *e-news* features dates and locations for our 2018 Walks to d'Feet on page 4 and a truly comprehensive list of MND NSW Support Services events for 2018 on pages 10 and 11. These events for people living with MND, families and carers are provided at no charge to those attending. This is only possible through the continued support of community fundraisers, such as those listed on page 12. Thank you for your efforts.

Thank you also to the staff from the Department of the Environment and Energy in Canberra (pictured above) for their ongoing support through the Scott Lisle Memorial Ice Bucket Challenge held annually in memory of Scott, a former colleague. Staff braved the ice bucket in November 2017 raising \$7,000 towards support for people living with MND and MND research.

*Graham Opie*



MND NSW provides information, support, education, services for people living with motor neurone disease, their families, friends and carers, health, community and residential care professionals in NSW, ACT, the Gold Coast and NT.

## Newcastle Italian Film Festival

Thank you to Nick Moretti from the Newcastle Italian Film Festival for your continued support and donation of \$15,000. This is the fourth year that MND NSW has been supported by the festival. Pictured is Nick Moretti (left) and Graham Opie, CEO MND NSW.



## Make a difference

To make this year's the biggest Blue Cornflower Day yet, we need your help.

Can you spare a few hours on Friday 11 May to collect donations and sell merchandise at railway stations on the Sydney network or at a local shopping centre?



We need to raise MND awareness and funds to continue the work of the Association because *Until there is a cure, there is care*. If you can help contact Sarah Bouch, Volunteer Coordinator, ph. 02 8877 0928 or [sarahb@mndnsw.asn.au](mailto:sarahb@mndnsw.asn.au).

## NSW researcher awarded prestigious prize

We are proud to share that the winner of the MND Australia Betty Laidlaw MND Research Prize announced in November 2017 is Associate Professor Justin Yerbury from the University of Wollongong (pictured right).

This \$250,000 grant is awarded to an outstanding mid-career researcher and made possible thanks to the generous sponsorship of John Laidlaw AO in honour of his wife, Betty, who is living with MND.

Associate Professor Yerbury's project will investigate dysfunction of proteins in nerve endings as a cause of MND. Congratulations Justin and thank you for your work.



## Media announcement of new drug trial in Australia of Tecfidera for MND

An Australian trial of the drug Tecfidera for MND was reported in 'The Age' newspaper on 21 December. The Australian TEALS (Tecfidera in amyotrophic lateral sclerosis) study is a multi-centre Phase 2 clinical trial to investigate the safety, tolerability and effectiveness of a drug called Tecfidera in people with MND. Tecfidera is currently used to treat relapsing multiple sclerosis (MS) in Australia by slowing down the progression of physical disability of MS. You can find more information about the Australia TEALS Study here <http://www.mndaust.asn.au/Discover-our-research/Latest-research/Clinical-trials/TEALS.aspx>. You can read more about Tecfidera for relapsing multiple sclerosis here <https://www.nps.org.au/medical-info/medicine-finder/tecfidera-capsules>.

## Living Well with MND Information Day

20 March at Bossley Park

25 May at Port Macquarie

25 September at West Ryde

*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

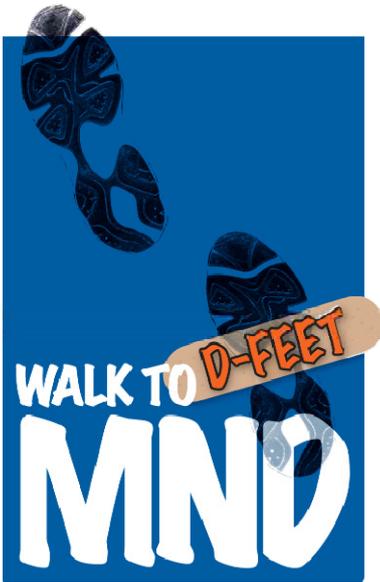


opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND. There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.

## 2017 Christmas Appeal

Our 2017 Christmas Appeal raised over \$45,000 to help support people living with MND. Thank you to all who contributed. Thanks also to Ann Ridd and the Ridd family for talking about MND as part of this Appeal and for their ongoing commitment to raising awareness about MND in the community.

## Together, let's take steps to d'Feet MND



Join us at a 2018 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 motor neurone disease.

Why not join in the fun at a 2018 Walk to d'Feet MND?



18  
Feb

**Walk to d'Feet MND Illawarra** *Supported by*  
Bulli Surf Club  
Bulli

Register now



25  
Mar

**Walk to d'Feet MND Hunter** *Supported by* **LeahJay**  
Dixon Park, Merewether



24  
Jun

**Walk to d'Feet MND Canberra** *Supported by*  
Peace Park, Parkes, ACT



15  
Jul

**Walk to d'Feet MND Penrith** *Supported by*  
International Regatta Centre, Castlereagh



26  
Aug

**Walk to d'Feet MND Batemans Bay** *Supported by*  
Corrigans Beach Reserve, Batehaven



16  
Sep

**Walk to d'Feet MND Port Macquarie** *Supported by*  
Westport Park, Port Macquarie



14  
Oct

**Walk to d'Feet MND Wagga Wagga** *Supported by*  
Apex Park, Wagga Wagga



**Les Gray Plumbing**

4  
Nov

**Walk to d'Feet MND Sydney** *Supported by*  
Blaxland Riverside Park, Olympic Park



For more information see <http://www.mndnsw.asn.au/get-involved/walk-to-dfeet-mnd.html>.

### Past Carers Lunch

20 February at Hamilton, Newcastle  
26 March at MND NSW Centre Gladesville

This is a lunch and get together for people who have experienced bereavement during the last year. This occasion provides an opportunity for you to reconnect with old friends from MND NSW and to meet others who have cared for someone with MND. After lunch there will be a talk and discussion about some of the experiences of bereavement and possible ways to manage these. There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.



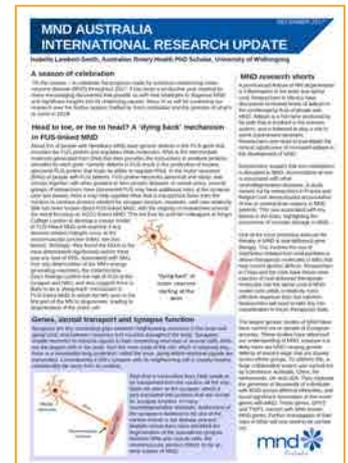
### Advance December 2017

In the December 2017 edition of *Advance*, the newsletter of the MND Research Institute of Australia (MNDRIA) - the research arm of MND Australia, read about the *\$25 Million, 25 Milestones: Changing the future of MND* report launched in November 2017. Also listed are the 2018 MNDRIA grant recipients of the exciting \$3.31 million newly distributed following a comprehensive process that ensures funding is allocated to research projects that have the greatest chance of making a difference for people with MND.



### MND Australia Research Update December 2017

This *Research Update* is produced by the MND Research Institute of Australia - the research arm of MND Australia. In the December 2017 edition read the latest MND research news including a 'dying-back' mechanism in FUS-linked MND, axonal transport and synapse function, the promise of viral-delivered gene therapy in mouse trials, fungal protein infection research, protein clumps and MND and free radical damage and MND.



## A 70th birthday to remember in Cootamundra

In early 2017 Joanna Finlay's husband Royce (pictured right) was diagnosed with MND. For Royce's 70th birthday in September, Joanna and Royce decided to have an afternoon tea party and, in lieu of presents, they would do something for MND NSW. Joanna and friends shared the details by word of mouth, hardly expecting a big response. "All we wanted was for people to support a good cause and we thought maybe we would raise \$1,000 towards research."



Imagine her reaction and Royce's joy when friends travelled from Brisbane, Central Coast, Ballarat, Melbourne and Orange to attend, together with local friends and relatives from Cootamundra and surrounds. Royce had a very enjoyable 70th, which is especially poignant in hindsight because Royce died from MND in January 2018. Joanna and Royce were overwhelmed with the amazing response and support they received, with over \$5,000 raised. It was a massive show of love, friendship and support from Cootamundra and beyond.

## Craft Market Greystanes

A big thank you to the Craft Market Greystanes for choosing to support MND NSW with their annual market in November which raised \$5,447. With 38 stalls booked for the day the market was a great success and a good day was had by all. One stallholder and one sponsor of the event have had family members who have suffered from MND so they were extremely happy to provide their support. Thank you also to St Pauls Catholic College, Greystanes, who made a donation from their annual car show and barbeque on the day.



Are you caring for someone with MND? Do you want to increase your knowledge?

15 May, 22 May, 29 May and 5 June at MND NSW Centre Gladesville

*Care for Carers* is a supportive educational program for those caring for a family member or partner with motor neurone disease. Care for Carers runs once a week for four weeks and participants attend all sessions. Here is what some of the carers who participated last year had to say:



*"The new knowledge and confidence I gained during the program was invaluable for me. It's never too early to do this course."*

*"I now feel stronger and confident of my ability to care for my wife."*

*"It was wonderful to get to know others with a family member with MND and we all learnt so much from each other. I was hesitant to do this course and I am so happy now that now that I made the time to come along!"*

There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd/183-care-for-carers-2018-wk1.html>.

If you are unable to attend this dates, yet would like connect with others and gain support, Carers NSW is offering a therapeutic *Grief and Loss Talk-Link* telephone support group. This group facilitated by counsellors for an hour weekly for six weeks. To learn more about the *Grief and Loss Talk-Link*, contact Carers NSW Carer Line ph. 1800 242 636.

## For Sale

2003 Mercedes Benz Vito 112 CDi Mobility Van, 2.2 Litre Turbo Diesel, automatic, includes custom fixtures and lift for mobility wheelchair, mag wheels, low kilometres....approx 49,000, very good condition, silver colour. Wheelchair front passenger, all seats and console available with Van. Reg. to April 2018. \$20,000 ono. Phone Carole 0408 439 775.

## Upcoming community fundraising events

Click to find out more.

**18 Feb** **4th MND Charity Concert**  
Glendale



**6 May** **Run MND 2018**  
Sutherland to Cronulla



**11 May** **7th Annual Riddla MND Golf Fundraiser**  
Twin Creeks Golf and Country Club



**13 Oct** **Gundaroo Music Festival 2018**  
Gundaroo Park



*Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? <http://www.mndnsw.asn.au/get-involved/fundraise.html>*

## Submissions open for 2018 MND March of Faces Banner

Australia's MND March of Faces Banners are a photographic display of people with motor neurone disease. The banners are displayed at various MND awareness raising and remembrance events throughout the year. Our 20th banner in the MND March of Faces series will be displayed during MND Week 2018.



If you have MND and would like to be included in the new banner, you need to complete a permission form and submit a photograph of yourself. Family members are also able to submit a photograph in remembrance of a person who has died from MND. [More info here.](#)

## Upcoming Support Service events

Click to find out more.

13  
Feb

**Information Evening for people recently diagnosed with MND**  
Gladesville

20  
Feb

**Past carers lunch**  
Hunter

20  
Mar

**Living Well with MND**  
Bossley Park

26  
Mar

**Past carers lunch**  
Gladesville

17  
Apr

**Information Evening for people recently diagnosed with MND**  
Gladesville

5  
May

**Day of Hope and Remembrance**  
Homebush

15  
May

**Care for Carers 15 May, 22 May, 29 May and 5 June**  
Gladesville

25  
May

**Living Well with MND**  
Port Macquarie

19  
Jun

**Information Evening for people recently diagnosed with MND**  
Gladesville

14  
Aug

**Information Evening for people recently diagnosed with MND**  
Gladesville

17  
Sep

**Past carers lunch**  
Gladesville

*(Continued on page 11)*

(Continued from page 10)

## Upcoming Support Service events (cont'd)

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**25**  
Sep **Living Well with MND**  
West Ryde

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**16**  
Oct **Information Evening for people recently diagnosed with MND**  
Gladesville

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**5**  
Nov **Ask the Experts Forum**  
West Ryde

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**4**  
Dec **Information Evening for people recently diagnosed with MND**  
Gladesville

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Upcoming Support Service events for health and community care professionals, service providers and NDIA staff

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**15**  
Feb **Supporting NDIS participants Living with MND**  
Wollongong

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**14**  
Mar **Supporting NDIS participants Living with MND**  
Burwood

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**10**  
Apr **Supporting NDIS participants Living with MND**  
Kogarah

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**24**  
May **MND Aware**  
Port Macquarie

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**2**  
Aug **MND Aware**  
Gladesville

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**25**  
Oct **MND Aware**  
Wollongong

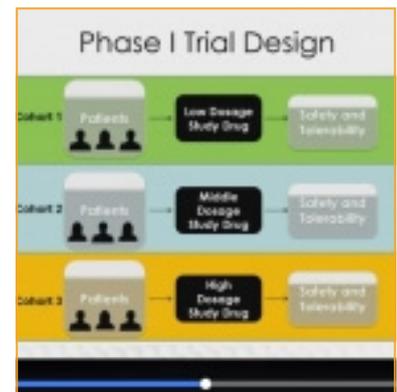
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See <http://www.mndnsw.asn.au/all-events.html> for more information

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## 2017 International Ask the Experts 6 December webcast recording now available

The 2017 International Ask the Experts took place on 6 December in Boston USA. This event was designed for people living with ALS/MND, carers and families and the webcast recording is now available free online. You can access the recording on the International Alliance of ALS/MND Associations' Facebook page <https://www.facebook.com/TheIntlAlliance/>



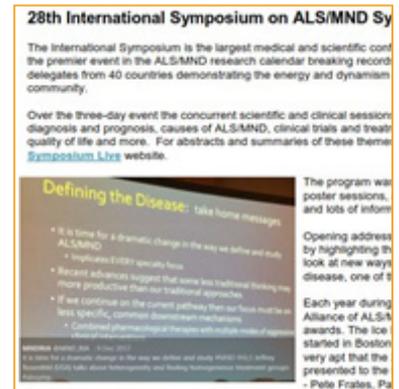
## We appreciate your support

There were many community events held across NSW and ACT during 2017. Special thanks go to each and every organiser who gave so generously of their time to raise funds for MND NSW and awareness about MND. Thank you to the following organisers and supporters of events held during 2017 not previously acknowledged in our e-news.

- Deidree Jones who, for many years, has sold MND merchandise, held raffles and collected donations in the Batemans Bay area.
- Helen Kemsley and everyone who participated in the Annual Kemsley Cricket Match which raised \$937.
- Wendy Clissold who raised \$411 from a raffle of a handmade knitted Paddington Bear.
- The Illawarra Chilli, Spice and All Things Nice Festival organised by Amie Holder which raised \$3,479 for MND NSW.
- A donation of \$135 from the children of Donvale Christian College who worked hard selling cakes, drinks and other items.
- The women from the Windsor Country Golf Club who donated \$1,065 from their Charity Day.
- A donation of \$450 from the class of Year 12, 2017, Hunter River High School.
- The school community of Warrawee Public School for their continued support, and recent donation of \$3,730.
- Lyn Pennock and helpers who held a Christmas stall at Chester Square, with lovely handmade crafts raising \$3,400.

## Wrapping up the 28th International Symposium on ALS/MND, Boston, December 2017

*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 at the end of 2017 with over 1200 delegates from 40 countries demonstrating the energy and dynamism of the global ALS/MND research community. Here is an update on Symposium happenings and news from Carol Birks, CEO, MND Australia.*



"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](#).

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 from Jeffrey Rosenfeld set the scene by highlighting the need for the research community to look at new ways to tackle the heterogeneity of the disease, one of the major challenges of MND.

Each year during the opening session the International Alliance of ALS/MND Associations presents two awards. The Ice Bucket Challenge phenomenon all started in Boston in August 2014 and it was therefore very apt that the 2017 Humanitarian Award was presented to the three men who initiated this challenge - Pete Frates, Pat Quinn and the late Anthony Senerchia. The award was accepted on their behalf by Pete's mother Nancy Frates. 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. Last year's Forbes Norris recipient, Dr. Mamede de Carvalho presented the 2017 award to Boston based neurologist and researcher Merit Cudkowicz, The annual

Paulo Gontijo Prize in Medicine was awarded to Dr Marka van Blitterswijk of the Mayo Clinic in Jacksonville, Florida. The Award is presented to an outstanding young investigator working on ALS/MND. Read about her work [here](#).

Research highlights from the Symposium included the discovery of two new genes linked to MND and the use of antisense oligonucleotide-based therapies, which is looking hopeful for people with SOD1 and C9orf72 mutations.

Presentations on expanded/pre-approval access to potential therapies stimulated discussion. As always the inimitable Richard Bedlack entertained whilst challenging us all to reflect on our views and practice.

The multi-step process of MND progression and factors such as genetic mutations that may shorten this process was a feature of a number of presentations. You can listen to Professor Al-Chalabi's talk at previous conference on this theory [here](#).

Clinical highlights included presentations on carers and cognitive change, telemedicine, app development and much more. The MND Association research blog ['There's an app for that – the wonders of technology in ALS'](#) provides an overview of some of these presentations.

There were a number of sessions that covered clinical trials highlighting the worldwide research focus on the search for an effective treatment but also the complexities associated with this search. For an overview of the clinical trials session take a look at the [MND Association blog](#). We were all disappointed to learn that the phase three trial of tirasemtiv was negative but will watch with interest the current investigation by the European Medicine Agency (EMA) on Masitinib which has shown a slowing of progression in a phase 2/3 trial. Further clinical trials will be conducted to provide more necessary information (including higher dosage effects) to the EMA.

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For further highlights check out more MND Association research blogs:

- [Causes, treatment therapies, biomarkers and clinical trials](#) – Mary-Louise Rogers (Adelaide) findings on her study looking at a protein called p75, which is shed from injured nerve cells and traces of it can then be found in urine, as a potential biomarker is featured.
- [Clinical Management](#) - covers presentations on recent advances in respiratory support, technology, neck support and more.
- [Not just about the neurones](#) – the role of glial cells formed the theme for Session 9A on the last day of the meeting. There are several types of glial cells found in the CNS, but researchers have largely focused their attention on two particular members of the glial cell family: astrocytes and microglia. Australian researcher Marco Morsch (Sydney) findings on his study that shows microglia can help to mop up proteins such as TDP-43 when they leach out of sick or injured cells is featured.

Once again, the Australian contingent of researchers made their mark. The MND Research Institute of Australia (MNDRIA) is proud to have funded nine of the Symposium presenters including Beryl Bayley MND Research Fellow, Dr Parvathi Menon from University of Sydney. Parvathi reported that cortical hyperexcitability is a regional phenomenon in MND, most prominent in cortical areas representing the hand region.

Dr Marco Morsch from Macquarie University presented some elegant research using zebrafish to visualise microglial activation in real time highlighting the ability of microglial cells to uptake TDP-43 and showing if this does not happen there is abnormal dispersal of TDP-43 into neighbouring tissue. Dr Frederik Steyn of The University of Queensland discussed the association of hypermetabolism with lower motor neurone burden and functional decline. Dr Nimeshan Geevasinga from University of Sydney studied 305 people with MND and found cortical excitability scores may be a useful novel biomarker for diagnosing MND.

The Aussies were also out in force for the poster session and congratulations to Dr Mehdi Van Den Bos from University of Sydney, who stood out in a field of 450 to be awarded a prize for his poster 'Imbalance in cortical inhibition-excitation networks underlies the development of cortical hyperexcitability in ALS'.

We were all enormously proud of the strong Australian presence at the Symposium and the big part MNDRIA has played in making this happen.

You can [view some of the posters and slides](#) uploaded by presenters to the MND Association 28th International Symposium website and also @mndaustralia @MND\_RIA #alssymp on twitter, for further insights and highlights.

A new initiative spearheaded by ALS TDI introduced funding to support people living with ALS/MND to attend the Symposium. Six Patient Fellows were awarded and [this blog](#) written by some of the Fellows provides further insights on the presentations from the perspective of a person living with MND and caregivers. One of the Fellows commented "One of the purposes of the ALS/MND Patient Fellows program was to make sure the patient perspective was not lost in the scientific proceedings. Overall, I was deeply impressed by how connected most of the discussions were to the patient experience. In hindsight, I think there were two areas where the patient voice could have been stronger: invasive ventilation and ineffective placebo arms in trials".

This year the 'patient' voice was louder and stronger with many presenters acknowledging people living with ALS/MND as integral to their research outcomes and the inspiration for their work.

The highlight of the closing session was therefore the presentation of the inaugural Shay Rishoni Patient Impact award to Bernard Muller and Robbert Jan Stuit founders of Project MinE and Treeway. Two people living with ALS/MND who have made a huge impact on research globally.

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The meeting wrapped up with an invitation from MND Scotland to attend the International ALS/MND Meetings in Glasgow from 4 to 9 December 2018.

During 2018 we will be working with the MND Association Conference team, the International Alliance of ALS/MND Associations and MND WA to finalise details for the 30th International Symposium on ALS/MND to be held in Perth from 1 to 6 December 2019. Mark your diaries now - let's make Perth 2019 a record!"

*Carol Birks, CEO, MND Australia*

[View presentations from the 15th Annual Allied Professionals Forum, Boston, December 2017](#)

The International Allied Professionals Forum enables health and community care professionals working with people living with MND to share ALS/MND care and support innovations. This helps guide the practice of these professionals worldwide.

Over 250 delegates attended 15th Annual Allied Professionals Forum, Boston, in December 2017 to hear 16 presentations covering a wide variety of topics for health and community care professionals including resource development, carer and family support, cannabis use, respiratory care and innovative approaches to assistive technology provision. You can watch the presentations free online at YouTube by following the following links:

View the [full playlist of the 15th Annual Allied Professionals Forum, Boston, December 2017](#) or select an individual presentation

1. [Meeting the Changing Needs and Increasing Numbers of Those Living with ALS/MND](#), Patricia Stanco
2. [Improving Patient Care: The Development, Delivery and Initial Evaluation of the Introduction of an Orthotist into a Well Established Specialist ALS/MND Clinic in Order to Prolong Function](#), Nathalie Lucas

*(Continued on page 18)*

*(Continued from page 17)*

3. Developing a Suite of Resources to Support Implementation of the NICE Guideline on ALS/MND in England, Wales and Northern Ireland, Rachel Boothman
4. Developing an Eating and Drinking Guide to Improve Quality of Life for People with ALS/MND, their Carers and Families, Kaye Stevens
5. Families and ALS/MND: Development of a Resource Guide for Talking with and Supporting Children and Youths, Melinda S. Kavanaugh
6. Six Months Sequential Sessions: A Novel Approach to Improve Participation in Family Peer Support, Merete Vaegter
7. Genetic Counselling in ALS/MND Multidisciplinary Care: Insights and Challenges, Ashley Crook
8. ALS/MND Web Based Educational Resources: Collaborative Effort, Krista Strait-Higgins
9. The 'Model of Doing' for People with ALS/MND, Helen Carey
10. Advancing Respiratory Care in the ALS/MND Clinic, Denise Martins
11. The Impact of the Edinburgh Cognitive and Behavioral ALS Screen (ECAS) Master Classes: Training Health Professionals to Identify Cognitive and Behavioral Change in ALS/MND, Faith Hodgins
12. Cannabis and its Usage in Symptom Management of ALS/MND, Leslie Ryan
13. Power Wheelchair Advanced Features and their Impact on Function, Amber Ward
14. A Revolutionary Approach to Assistive Technology for 'Locked In' Patients, Or Retzkin
15. Making Your Home a Smart Home, Sara Feldman



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...and many valued  
volunteers