

## MND NSW in the **communications** age

### A message from the CEO

You often hear the times we're living in referred to as the communications age. Increasingly frequent communications using a more and more bewildering array of digital devices seems to be part of modern life. But in the last year I was reminded why communications are especially important to our members struggling with MND. As Duncan Bayly, a member of MND Victoria said in his address to the 8th National MND Conference in 2016, "...the most critical goal for many people living with MND, and the key to reaching further goals, is the ability to communicate itself."

In line with this insight, we have worked hard in the past year to support our members in achieving key communications needs. We have helped them with the communications challenges presented by daily life. We have reorganised and augmented our team to facilitate the individualised pre-planning and third-party communications necessary to help members aged under 65 years make the most of their NDIS plans. We have continued to work on communicating our cause to the public in order to fund research that will lead to a cure. And, we have improved our own communications with our members—sharing the first glimmerings of hope in the latest genetic research and drug development, and offering connection and support through new digital channels.

In the following pages I am proud to introduce our reconfigured team and to summarise some of its achievements. I am mindful, however, as with the close of every year, that there is still much more to be done.

To all those who have lost loved ones and friends to MND, on behalf of our board and staff, I extend our deepest sympathy.

*Graham Opie*

Chief Executive Officer

## Communications in daily life

### Communication Apps and Tablets

For members who have difficulty speaking or are unable to talk, communication applications (apps) are available that can be run on portable devices such as smart phones or tablets. With the applications, these devices display or sound words in response to input from a keyboard or a digital communication chart. For a while now, FlexEquip has been offering free two-week trials of iPads preloaded with a range of apps, allowing members to work with their speech pathologists to determine the communication app most suitable for them. Once the best app has been selected, FlexEquip can provide members with an iPad loaded with the app, or members can purchase the app for use on their personal devices. In the past financial year, 110 iPads loaded with communication apps have been provided by FlexEquip to MND NSW members.



# Communications in daily life

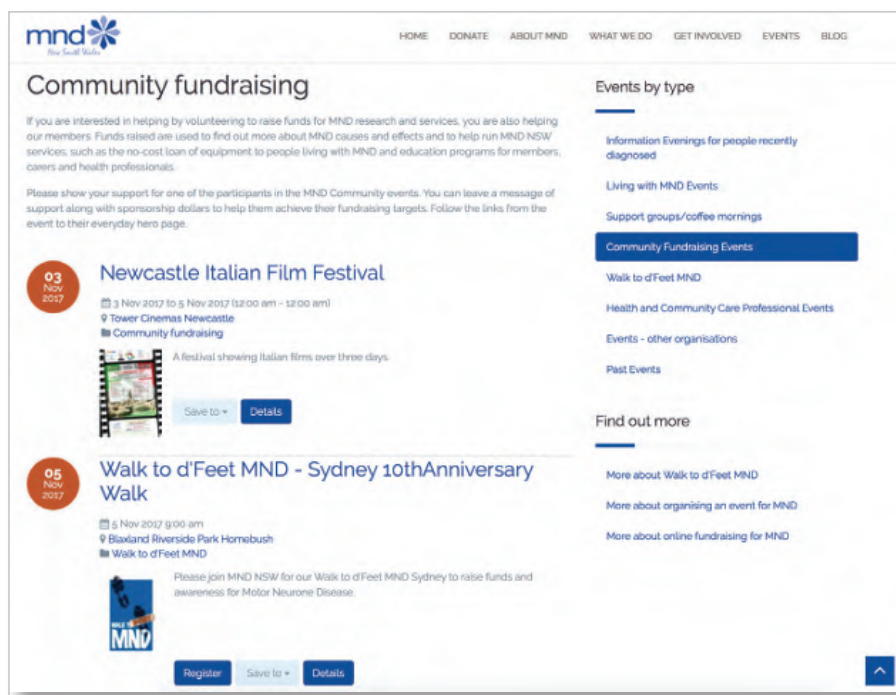
## Voice and Message Banking

The latest voice and message banking technology may make life easier for people with MND. To ascertain if this is the case, and to determine the technology choices most suitable in terms of cost and complexity, MND NSW has been working with business and design students from the UTS Shopfront Community Program. The project kicked off in April, 2017. A report of the student consultants' findings is expected in November, 2017.



## Improved communications to our members

This past year has seen us take greater advantage of digital communications. Our new monthly e-news newsletters allow us to provide more – and more current – information to our members. (A quarterly print News roundup remains available). A new online events calendar also allows members to view all MND NSW events, including support group meetings, by date or search for them by category.



## Let us communicate with you

If you would like to receive e-news, our monthly update on educational events, fundraising activities and the latest developments affecting people living with MND, please call 02 8877 0999 or email [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au).



# Communicating needs to NDIS and third-party suppliers

Having experienced the recent NDIS roll out, we believe it would be impossible for our members to get the most out of their NDIS plan without careful preplanning and dedicated support in communicating with the NDIS, and with service providers and allied health professionals. Thus, to ensure that our members get the help they need, we have reconfigured and augmented our team to include six Coordinators of Support (COS) dedicated to helping our members coordinate the services in their NDIS plan, a COS Administrative Assistant, and a COS Team Leader. This new COS team works in conjunction with our existing MND Advisor and FlexEquip services to assist our members in identifying and negotiating with service providers that best meet their needs.

## Coordinators of Support



**Alexandra Matouk**  
*COS Team Leader*



**Brenda Smith**  
*COS Administrative Support*



**Kristie Stamford**  
*South Eastern Sydney & Inner West Sydney*



**Anna Fisher**  
*Western Sydney & Blue Mountains*



**Jasminka Gojkovic**  
*South West Sydney*



**Kim Sinclair**  
*Hunter New England*



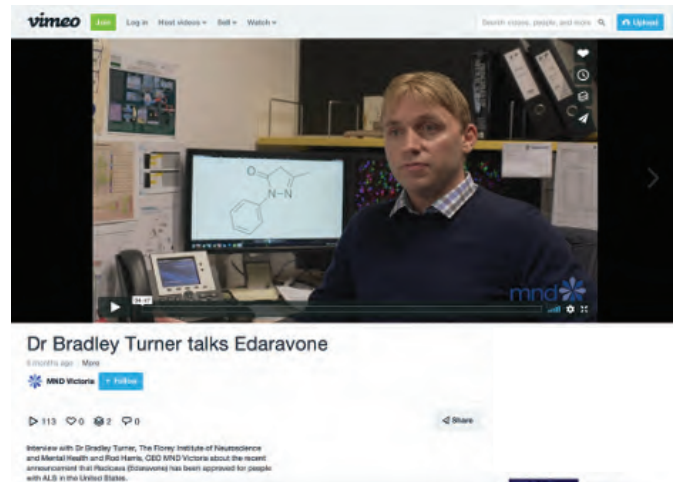
**Marnie Roelink**  
*Central Coast*



**Samantha Potter**  
*Illawarra*

# Communicating hope

On May 5, 2017, the U.S. Food and Drug Administration (FDA) approved the drug Radicava (edaravone) to treat ALS/MND in the USA, the first drug to be approved for MND/ALS in more than 20 years. We were able to post to our YouTube channel a videotaped interview with Dr. Brad Turner of the Florey Institute of Neuroscience and Mental Health, Victoria, about what this development means for Australians. In the same way, we have made videos of MND Connect 2016, a forum on MND research, and International Ask the Experts available on our YouTube channel.



On the research front, this past year has seen progress in the search for an MND biomarker (Urinary p75ECD), the announcement of four new genes associated with MND (C21orf2, MOBP, SCFD1, ANXA11), and the confirmation of another (NEK1).

Digital technology has allowed us to link out from our e-news to the research blogs of MND associations around the world discussing and explaining these developments, and sometimes to the full papers themselves. We were also able to link to a special report on the key MND research hot topics from the 27th International Symposium on ALS/MND, provided by Isabella Lambert-Smith (PhD Candidate, Illawarra Health and Medical Research Institute).



Needless to say, this depth of information would not have been possible were we to rely simply on print communications.

## Communicating your support

All the progress that has been made – in the quest to understand MND, in the search for a cure, and in improving our communications and support for our members – would not be possible without the help of our donors. Voice your support for us with a donation. Please go to 'Donate' at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) to make a secure donation online with a credit card, or download a form to fill in and send with your cheque in the mail. Of course, you can always phone us at 02 8877 0999, if you prefer. If you would like to make a gift to MND NSW in your will, please contact us at 02 8877 0999 for a confidential discussion.



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