

## **Dystonia Network of Australia Inc. President Report for 2021/2022 Financial Year**

Dear Members,

Thank you for your ongoing support throughout the 2021/2022 financial year. Our membership stands at 265.

We have had a busy year and have continued our pivot towards online work due to COVID-19 and related restrictions. Our last AGM was held on 15<sup>th</sup> December 2021 and had to be held via Zoom due to Covid issues.

At the commencement of the financial year, we sought consultation with the NSW government in relation to a NSW Liberal Party promise of a package of \$8.6 million to boost specialist nurses and allied health staff for people with movement disorders. We had several questions relating to issues such as the proposed model of care, outcome measures, eligibility, training, and resources. The government rolled out the program in 2022 and it aims to place a specialist nurse or allied health professional in each NSW Local Health District. Laraine, due to her background as a neurological Clinical Nurse Consultant, was involved with nurses from the Movement Disorders Chapter of the Australasian Neuroscience Nursing Association in writing up the first dystonia paper which will lead to a training module for nurses wishing to further their knowledge in the care of people with dystonia.

Unfortunately, we had to make the decision to end support for the Dystonia App that was launched in 2020. Reasons were the high cost of maintenance and troubleshooting; low user take up and the app developer being unsuccessful with a grant application and gaining support from other health organisations.

Dystonia Awareness Week became Dystonia Awareness Month and was held from 1<sup>st</sup> to 30<sup>th</sup> September 2021, which brought us in line with the USA and much of Europe. It was conducted online due to COVID-19 and featured the following excellent webinars organised by DNA:

- Dr Tjerk Lagrand from the Netherlands, who was working in Queensland with Dr Alex Lehn, did a presentation on Functional Neurological Disorders.
- Dr Florence Chang presented on musicians'/forearm dystonia.
- Melani Boyce, physiotherapist, and PhD student, spoke about her research into dystonia.

These webinars can be accessed through our website and YouTube channel. We also sent our 30 second radio ad out to community radio stations and Denise was interviewed on a podcast called The Advocate. A wonderful community in Victoria held several fundraising activities for one of our members and managed to raise over \$4000 for dystonia research. We are enormously thankful for their efforts and we would like to particularly thank Trish Ipsen and Wendy Powell. We also raffled a painting by artist Linda Quimby. Many thanks to members who purchased tickets.

With a combination of the Victorian fundraising money and DNA funds, we were able to achieve our goal of contributing to dystonia research. We advertised for an Australian PhD student conducting research into dystonia and as a result we ended up awarding \$5000 PhD top up grants to two impressive PhD students who are conducting very worthy dystonia research. They are:

- Jordan Morrison-Ham who is a PhD student at Deakin University, Melbourne. Her research project aims to determine whether non-invasive brain stimulation techniques can help people with dystonia.
- Dr Joel Maamary who is a PhD student at the University of NSW and is employed in the Department of Neurology at St Vincent's Hospital, Sydney. His trial involves the safety and efficacy of MRI guided ultrasound (MRgFUS) in focal hand dystonia.

Both Jordan and Joel prepared short video presentations about their projects which are available on our website and YouTube channel. We congratulate them and wish them all the best for their research.

During the year we held two General Meetings via Zoom with member chats afterwards. These Zoom chats have proved popular, so we are continuing them on a regular basis.

Towards the end of the year, Denise began to assist me with content on the DNA website. We are continuing to add new content regularly with a focus on research information and educational videos from Australia and around the world. Denise and I also participated in a Zoom meeting in June with neurocare nurses at the Neurological Council of Western Australia where we spoke about dystonia and the work of DNA.

We send our heartfelt thanks to all our members and to everyone who has donated to DNA. We have received some very generous donations through the PayPal Giving Fund and from the Ainsworth Family Foundation. We would like to acknowledge and thank our multidisciplinary advisory board for giving up their time to work for our charity. I would also like to thank our volunteer committee who have worked very hard during the year. The committee is finishing our two-year term this year. Elections for all positions will take place at this AGM.

I would like to take this opportunity to wish our outgoing committee, the advisory board, DNA members and your families a very safe and happy Christmas and New Year.

Warm Regards,  
Kerrie Jackson. DNA President and Co – founder.