

## President's Report AGM December 2018

Dear Members. Welcome to DNA's fourth Annual General Meeting.

At this meeting all the committee will be relinquishing our positions and a re-election will take place. We will let you know the new office bearers and committee members after voting takes place.

DNA remains solely run by volunteers with only a few people involved in the running of the organization. Our growth and legal requirements depend on these people who devote many, many hours of their time, we would really appreciate more involvement from other members as there are many things that could be done online which would leave us free to attend to the more formal side of the organization.

Membership is growing steadily and stands at present at 160.

A big thank you must go to our Advisory Board who provide us with their expertise and are extremely generous with their time and are always willing to answer general questions sent to us from our members.

Over the past 6 months our DNA web site stats have once again been staggering, rising steadily to 3,455 users who have had 4,407 sessions and they have looked at a total of 18,999 pages this is about 3,500 more pages than the same period last year. Please go to our web site regularly for updates and links on our media news and press release pages.

As DNA is the National Peak Organization for all Dystonias we made an application to the Australian Health Department for a national dystonia awareness week. This was granted and is now on the [health.gov.au](http://health.gov.au) web site for all Australians who suffer from Dystonia. The week requested and granted is September 14-21 inclusive. We are still hoping that New Zealand will join us soon.

As promised Laraine and I contacted the NDIS head office and spoke to them about having Dystonia on their Disability Requirements List. However, we were told that even though Dystonia wasn't on the list it doesn't mean that you wouldn't be eligible for the NDIS. The NDIS is evidence based on your disability and your impairment needs to impact significantly on your life to qualify for NDIS intervention.

Our 10<sup>th</sup> brochure Tremor in Dystonia is now available on our web site with some information sheets on the rarer forms of dystonia coming soon.

**New Wollongong Dystonia Support Group** for those wishing to be part of this group please contact Kerrie Phone: 0414 648 571 or Email: [info@dystonia.org.au](mailto:info@dystonia.org.au) for more details. **Please Note:** You do not need to be a member of DNA to be part of this group. It is open to all who need support for dystonia and would like to have a coffee and a chat in the Wollongong and surrounding areas. Contact details will remain in Professor Carmody's Botox clinic. We are hoping the Support Group will start early next year.

Those members who are visiting the Children Hospital Westmead might like to go to the Neurophysiology Department at the entry to the consultation rooms to see 2 very beautiful and vibrant children's paintings that were painted and donated by one of our members.

Laraine McAnally was DNA's representative at the New Zealand Dystonia Patient Network (NZDPN) Meeting this year. She was very impressed with the presentations and friendly atmosphere and has written a comprehensive report in the newsletter which will be out in the next week.

The Movement Disorder Society of Australia & New Zealand – Laraine and I attended this event in September 2017. We met with many medical, nursing, allied health and pharmaceutical companies creating the very important Dystonia and DNA Awareness links.

On behalf of our committee and members I would like to sincerely thank these very generous people and companies for their kind donations to DNA this year: Macquarie Bank for Brad Coleman / Paul Ainsworth Family Foundation / Medtronic grant for our 2017 Seminar. Also thanks to Merz Pharmaceuticals who have once again donated 100 translated copies of Jean-Pierre Bleton's book for physiotherapists – Spasmodic Torticollis – A Physiotherapy Handbook –

Last year's seminar – another successful seminar held at Hotel 175 Westmead – was well attended and included expert clinicians in the field of dystonia. The presentations, with Professor George Mellick from Queensland as the keynote speaker, were excellent. Unfortunately our attempt at videotaping the seminar was not successful as we did not have the funds for professional videotaping.

I would like to close by wishing all our members and their families a very Merry Christmas and a safe and Happy New Year.

Warm Regards

A handwritten signature in dark ink, appearing to read 'K. A. Jackson', with a stylized flourish at the end.

Kerrie Jackson DNA President.