

President's Report by Kerrie Jackson

Dear Members,

Welcome everyone to DNA's third Annual General Meeting on 10th December 2017.

At last year's AGM we voted in our office bearers and committee for a term of two years so unless we have any office bearer or committee member wishing to relinquish their position, there will be no voting of positions at this year's AGM.

Our mission over the past year has been public awareness and to become known to as many Neurologists as possible. I think there is no doubt that DNA has achieved this. We are extremely happy to see our Logo starting to appear on many Movement Disorder Specialist, allied health and company websites that have an interest in dystonia, across Australia and New Zealand.

DNA now has 117 members; with the help of google analytics DNA's website over the past 90 days has had 1,703 sessions with 1,278 people who have viewed 7,778 pages. These stats certainly show that DNA has overwhelmingly achieved its goal.

DNA is run solely as a voluntary Incorporated Organisation. We have over 70 pages of information on our website and adding and changing content is a fulltime job. We try to update as often as possible but this is only part of running the organisation. Our press release and news stories pages are used for advertising on the DNA website. You are very welcome to email us with the details of any Dystonia events that you would like advertised. If the event is for a Dystonia Support Group meeting, please state this in the email.

We now have 9 Brochures available with the 10th "Tremor in Dystonia" written by Dr Stephen Tisch now at the printers and available very soon. The first draft of the Carer's Fact Sheet has come back from the Advisory Board and will be finalised early next year. All our brochures are on our website and are now available for anyone to download - **you do not need to be a DNA member to do this.**

The Inaugural ACT Dystonia Support Group Meeting.

Founding members: Kerrie, Fiona, Trish, Gerda, Lornie and Marie. Apologies from Susan, Margaret and Annette.

On Wednesday 14th December 2016, Fiona, who is a member of DNA and lives in Cook in the ACT, and myself hosted a luncheon for the new Dystonia Support Group in Canberra and Surrounding Districts. The group has been put together to provide a safe environment for sharing experiences and concerns with other people with dystonia. Many new friendships were formed that day giving comfort, as most people there had never had face to face contact with anyone else with dystonia. You do not have to be a member of DNA to attend this support group as it is open to everyone with dystonia who needs support, as well as their carers and family.

If you are interested in having contact with this group, please contact Kerrie on (02) 4784 3368 / 0414 648 571 or you can email us at info@dystonia.org.au

We would like to sincerely thank these very generous people for their donations this year:

Donations by the family of the Late Zach Cannan \$310.00

SA Office, Commonwealth Department of Health and Margot Chiverton \$ 111.40.

Paul Ainsworth Family Foundation \$1,000

Brad Coleman and the Macquarie Group Foundation \$1,000

While visiting Professor Carmody and his team at the Botox Clinic in Wollongong Hospital, Laraine and I met with Linda Quimby who donated 2 wonderful children's paintings she had painted. We are hoping that these very colourful pieces of art will hang in the Neurology Ward and Clinical Room of the Children's Hospital Westmead. DNA will supply the plaques to go with these colourful masterpieces. A very big thank you to Linda.

We continue to strengthen our alliance with the New Zealand Dystonia Patient Network. Both Juliette Walker and I attended the NZDPN Conference which was held this year in Auckland. I have attached their recent newsletter which outlines some of the presentations:

<https://www.dystonia.org.au/wp-content/uploads/2015/05/November-Newsletter-2017.pdf>

As part of my presentation I put forward on behalf of DNA the importance of strengthening our ties with NZDPN, Blepharospasm Australia and other Dystonia Groups in Australia to work together for a

Dystonia Awareness Month/ Day or Week. Hopefully the awareness event will take place in September 2018 after the appropriate government authorities have been approached.

Laraine and I went to the Gold Coast for the Movement Disorder Society of Australia and New Zealand's Annual Scientific Meeting where we had a DNA booth. This was a great way for DNA to become known to all the Movement Disorder Specialists, particularly the soon-to-be Movement Disorder Specialists and all the other companies / booth holders who are involved with Dystonia.

We held another very successful Dystonia Awareness Seminar at Westmead on 29 September 2017. It was wonderful to meet everyone and put names to faces especially at the pre-seminar dinner. We had registrants from Adelaide, Melbourne, country NSW, ACT, Queensland and New Zealand. The venue suited us really well and the food was delicious. Our thanks to all the speakers, particularly our keynote speaker Professor George Mellick who came down from Brisbane on the day. Most of the other speakers were very generous with their time and stayed throughout the day. The presentations were excellent, and we were able to gain permission to video-tape all the sessions. They are in the process of being edited and we will be handing them to our web designer to put on the web site. We will let everyone know when they are available. There will be a small fee for those who were unable to attend the seminar to view the presentations. Our thanks go to Medtronic who were our sponsors on the day, to Peter Jackson who was our photographer and David Tsui who organised the video-taping and was a great technical help throughout the day.

Lastly, it was suggested and supported by A/Professor Victor Fung that Laraine and I approach the NDIS to ensure they accept Dystonia as a recognised neurological condition, not just a symptom and that it can cause serious disability. We will be following this up in the New Year.

Wishing everyone a very Merry Christmas and a safe & Happy New Year.

Warm Regards

A handwritten signature in dark ink, appearing to read 'K.A. Jackson'.

Kerrie Jackson DNA President