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## President's Report by Kerrie Jackson

Dear Members,

Welcome everyone to our second DNA Annual General Meeting. I would like to congratulate the outgoing office bearers and committee for a very full and extremely successful first term and wish the incoming office bearers and committee all the very best for an exciting and even bigger term of office.

**Membership:** DNA was opened for membership in May 2015. Since then DNA membership has been growing at a steady rate of 1 new member per week, with the current total of 82 members and a 25-member Advisory Board. We have alliances with Dystonia Europe and New Zealand Dystonia Patient Network. Our data base of non-financial members from all over Australia & New Zealand consisting of patients, allied health, nurses and medical contacts is growing at a very fast rate with around 300 people. We have recently added a meter to our website and the information registered is amazing. Over the last 90 days we have had a staggering 903 users who have viewed 7,701 pages which averages out at 8.5 pages per user.

### Fundraising:

\* **Trivia Night at Springwood Golf Club, 25 July 2015.** Our very first Fundraiser was held at Springwood Country Club who we would like to thank very much for their kind donation of the room and staff for the evening. The venue housed 100 people who enjoyed the charismatic quizmaster who made the event a fantastic success. He helped us raise \$3,500 after expenses from entry fees, bonus trivia questions and raffles. The funds raised went towards the printing and distribution of the dystonia brochures for Dystonia Awareness Month in September.

\* **City2Surf 9 August 2015.** This was the second year that Team Dystonia had entered the City2Surf Ann, Candy, Laraine & Claire all took part on the day, sporting the DNA Polo shirts and hats. \$1,220 was raised. It was a fantastic opportunity for a dystonia fundraiser and while Team Dystonia were walking, I spent the day raising awareness by handing out "What is Dystonia?" leaflets. Laraine and Claire both beat their last time by 10min.

\* **DNA Inaugural Benefit Night at Terranova Bar Restaurant, Horsely Drive, Sydney 28 April 2016.** Around 200 people gathered for dinner, auction and raffles. Unfortunately, we have not received the full amount raised on the night. So far we have received almost \$8,000. Terranova still owes us \$8,000. We continue to attempt to retrieve this money. Robyn and I went to see the owner of the restaurant on Thursday and were assured that the matter will be taken care of within the next week.

### Events:

**Inaugural Dystonia Seminar at the Garvan 14 August 2015.** A professor in Neurology from the Netherlands offered to give a presentation on dystonia while here on holidays in Australia. We felt this was too good an offer to refuse so we formed a committee comprising of Lynley Bradnam, myself and Laraine McAnally and organised the seminar in a matter of six weeks. We asked seven other people from our Advisory Board to speak on Dystonia. Doctor Ben Jonker spoke on tracing the history of neurosurgery through the ages and then discussed Deep Brain Stimulation (DBS). Doctor Stephen Tisch spoke about

Dystonic Tremor and Spasmodic Dysphonia. Our keynote speaker gave a most interesting address. Professor Marina de Koning-Tijssen presentation concentrated on an algorithm that has been developed for children and young adults with dystonia to make the journey to diagnosis much easier. She also spoke about "Dystonia Net (Cervical Dystonia arm)". This is a project of education and networking at many sites across the Netherlands to look at standardising the care of people with cervical dystonia. Melani Boyce and Professor Lynley Bradnam reviewed papers on the effect of exercise, biofeedback, sensory stimulation and transcranial magnetic stimulation mainly on cervical dystonia, focal hand dystonia and axial (trunk) dystonia. Doctor Florence Chang spoke about the Dystonia Coalition, a world-wide group of medical researchers and patient advocacy groups looking at research, treatments and a cure for dystonia. Included in their research discoveries are a new gene mutation for cervical dystonia, the role of the cerebellum on brain plasticity and guidelines for diagnosis of blepharospasm. Helen Brake spoke about her role as a speech pathologist in people with dystonia, looking at swallowing. She discussed the stages of a normal swallow and the swallowing problems associated with people with dystonia. Our last speaker for the seminar was Associate Professor Victor Fung who held a very informative and interesting question and answer session. We ended the seminar with a 'Jump for Dystonia' an initiative that started with Dystonia Europe. On behalf of DNA Inc., the committee and its members we wish to thank our keynote speaker Professor Marina de Koning-Tijssen for giving her time and great presentation, our fantastic DNA Advisory Board for all your time and support and Mr Peter Jackson for his photography in making our Inaugural Dystonia Seminar such a wonderful success. Without you this would not have been possible.

**New Zealand trip 7-9 May 2016.** Chris Gavenlock a DNA member and I attended The New Zealand Dystonia Patient Network Seminar for 2016 which was held in Rotorua. I was delighted to have been asked to be a guest speaker at the Seminar. I spoke about the origins, achievements and future of DNA. This was a great opportunity for us to cement our alliance with the New Zealand organisation. Chris and I were very grateful to the Patient Network for their generosity in providing payment for 2 night's accommodation and dinner at the seminar. Barry Snow, a movement disorder neurologist, and Julie Rope, a neurophysiotherapist, were also guest speakers and David Barton gave a report on the American National Spasmodic Dysphonia Association. Alison Fitzpatrick the NZDPN Chairperson spoke about her personal experience of Deep Brain Stimulation. The day finished with Chris and I as guests of the NZDPN at the seminar dinner. It was a perfect end to a wonderful day. Thank you to all!

**Australian & New Zealand Association of Neurologists Meeting in Perth 23-27 May 2016.** Laraine & I negotiated a free exhibitor booth (advertised as \$7,700!) in the exhibition hall. We met with many Neurologists and trainee Neurologists who visited the booth during the week. Since then we have had many more hits from neurologists on our web site. We also sent out around 20 packages to neurologist from all over Australia and New Zealand. This event was also good for us to touch base with Medtronic, Merz Australia, Allergan and Ipsen. Everyone was extremely happy and positive to have an Australian National Dystonia Organisation that they can go to for accredited information or refer their patients to the Advisory Board approved brochures, seminars, information on research and support. It was a wonderful event!

## **Other achievements**

**Printing and distribution of brochures.** 9 brochures have been written, edited and approved by the advisory board. 7 have been printed and hopefully the other 2 will be printed fairly soon. Packs of brochures have been sent out to members and neurologists in most areas of NSW and throughout most of the Capital cities in each state and through our members across Australia. If you notice that your MDS neurologist or Botox Clinic needs more brochures, please send us the details and we will send the packs out to them.

## **Merz Pharmaceuticals who donated 100 translated copies of Jean-Pierre Bleton's book for physiotherapists – Spasmodic Torticollis – A physiotherapy handbook –**

We must also acknowledge and give many thanks to Debbie Marques and Merz Pharmaceuticals who provided these books. They have been a great hit with physiotherapists in Australia. We would also like to personally thank Margot Chiverton for organising this with Debbie.

### **Plans for 2016- 17**

To reach out to neurologists in the other states, that we have not already contacted, sending packs and advertising DNA

Representatives to Movement Disorder Society Meeting

Representatives to NZDPN seminar

Dystonia Awareness Seminar in September 2016

Dystonia Seminar in another state if we can get the support

Allied Health Seminar on Dystonia

Wishing you all the very best,  
Kerrie Jackson  
DNA President.