

President's Report 2019

Dear members, it's a great pleasure to look back and reflect on DNA's activities over the past financial year July 2018 – June 2019. Our membership has grown to 183 but we service anyone in the dystonia community who contacts us for assistance or information. Our web site is well utilised STATS

During Dystonia Awareness Week (September 2018) DNA ran 2 seminars. One in Sydney and another in Adelaide: the Sydney day was in collaboration with the Department of Neurology at Westmead and the seminar was partially supported by Medtronic. The speakers, who gave up their time to support the organisation were leaders in the field of Dystonia but unfortunately both seminars were not well attended, and this impacted severely on our financial situation as we had both seminars professionally videotaped as requested by many members. There were also 2 Dystonia Awareness Days at Westmead Hospital and St Vincent's hospital.

We continue our alliances with like organisations and are now affiliated with some new organisations.

Laraine and Robyn made the trip over the ditch to New Zealand for the New Zealand Dystonia Patient Network Annual Seminar and as usual there were excellent presentations and a very warm welcome. Laraine gave a short update on DNA at the end of the day's presentations

DNA was invited along with over 400 health NPFs by the CC-DR (Centre for Community Driven Research) to attend the Inaugural Seminar for NFP organisations with the intent of developing an arm of this global organisation called APON (Australian Patient Organisation Network). Around 120 organisations were represented at the 2 day event that Laraine & I attended. The main aim is to allow patients to navigate the health system and be involved in the decisions for their care.

In May, myself, Laraine and Robyn attended the Australian and New Zealand Association of Neurologists held in Sydney. We had a booth and as well as meeting neurologists and trainee neurologists we were able to do some networking with other NFPs and Pharma groups.

We are now a member of the Health Consumer Forum which keeps us up to date with current health issues and offers the chance to be representatives on appropriate health panels

Also in May this year we had the first Wollongong Dystonia Support Group. Laraine, Robyn and I met with 10 local people with dystonia and all were very happy to finally have personal contact with others who have dystonia. We hope this group will continue to meet.

Our advisory board has lost Dr Paddy Grattan-Smith, a paediatric neurologist Grattan-Smith has retired. We now have Dr Julian Rodrigues, a Perth neurologist and Dr Muhamad Shakeeb, a paediatric neurologist, on board.

We continue to spread the word about Dystonia wherever we can, sending out our brochures all over Australia to neurologists, allied health, medical centres, physiotherapist and people with dystonia.

Denise and I attended an Accidental Counsellor Training Day at the Garvin Institute in June this year (Leadership meetings for Organisation with Genetic Alliance Australia). This was a very productive day. Our thanks to Genetic Alliance Australia and Lifeline for such a valuable presentation.

We were contacted by the Cystic Fibrosis Association to attend an Inaugural Not for Profit Forum in June '19 "What it takes to be an A-Team!" Laraine and I both attended and Denise was our consumer. The seminar was designed for leaders and consumers working together to find and try and solve problem within the respective areas we would like to thank the Cystic Fibrosis Association for such an insightful day and look forward to the results from the day.

Donations: our thanks to the Ainsworth Family Foundation, Elly Bath Birthday donation, and the anonymous donors through our funding alliances, such as PayPal, Benevity, Remember me and My Cause.