



Dystonia Network of Australia Inc. President's Report for the 2022/2023 Financial Year

Dear Members

As you may be aware, DNA has had a busy year which has involved some significant changes.

Change of President

Early in the financial year there was a change in the leadership of DNA. Unfortunately at a committee meeting on the 1st August 2022, our President Kerrie Jackson stepped down from her role due to health issues. Kerrie had been President of DNA since its inception in 2015 and I would like to acknowledge the outstanding job she did over those seven years as President. DNA would not be where it is today without her.

At that same meeting, the committee voted unanimously to elect me to fill the casual vacancy as President of DNA. I was honoured to have been given the opportunity to lead the organisation and appreciate the faith that the committee has in my ability to carry out this role.

Dystonia Awareness Month – September 2022

We were fortunate to be able to release three short educational videos during September:

- Mental Health and Dystonia by Dr Florence Chang
- Retraining for Task Specific Dystonia by Associate Professor Bronwen Ackermann
- Tardive Dystonia by Dr Stephen Duma

These videos can be accessed through our website and also our YouTube channel. We held a 'Jump for Dystonia' competition for our members, family and friends to raise awareness of dystonia. We also participated in radio interviews, ran our 30 second radio ad on as many local and community radio stations as possible and ensured neurologists' rooms were stocked with our brochures. Once again, the Goldfields Family Centre and Supported Playgroup in Victoria supported us by raising money, dressing in blue (DNA's colour) and engaging in lots of fun, blue themed activities. We thank them for their generous support.

Annual General Meeting

We held our annual general meeting on the 17th December 2022. Committee positions were declared vacant and the following people were elected to the committee:

Denise Duclos	President
Robyn McIlvar	Vice-President
Laraine McAnally	Treasurer/Secretary and Public Officer
Wendy Powell	Committee member
Dr Lyn Ryan	Committee member

Fortunately, Kerrie Jackson's health improved and on the 15th March 2023 the committee voted unanimously to elect her to a vacant position on the DNA committee. Therefore, as of the 30th June 2023 our committee membership stands at six.

Constitution

DNA is an incorporated association in NSW and operates according to a constitution which is governed by legislation. Our constitution has always been based on the NSW Fair Trading model constitution. Due to legislative changes, Fair Trading developed a new model constitution. Our committee was of the view that we should adopt the new model constitution in order to comply with the new regulation. Further, the committee was of the view that we should amend one of the three objects of our association (which are attached to our constitution). Our third object stated that we would 'ultimately' fund seminars and assist with research. We felt it was appropriate to remove the word 'ultimately' as DNA has been achieving these objectives.

At a Special General Meeting with members on 27th January 2023 the following two resolutions were passed unanimously and the Fair Trading model constitution is now in effect.

Resolution 1 – Dystonia Network of Australia Inc. adopt the NSW Fair Trading Model Constitution
Resolution 2 – Objects of the Association, third main object will now state – to fund seminars, educational forums and assist with research into dystonia

Funding for Australian research

In addition to the \$10,000 we awarded last year to two Australian PhD students who are researching dystonia, we were able to contribute further funds to research this year. This came about as a result of Courtney Law running her first half marathon on the Gold Coast in July 2022 to raise awareness and funds for dystonia research as her brother has a rare form of dystonia. Over \$4000 was raised by Courtney, her family and friends. DNA is very grateful for their efforts and in May 2023 we topped up the amount to \$5000 which we awarded to the research project being carried out in Melbourne involving a trial of non-invasive brain stimulation for cervical dystonia.

***healthdirect* Partnership**

In May 2023 DNA was approved as a Trusted Information Partner of *healthdirect*, the Australian government's national virtual public health information service. *healthdirect* has created a 'Dystonia' page and embedded links to many parts of our website. This is significant because it means our website meets their stringent standards and more people will be able to find our website and its resources.

DNA website and clinical information

During the year we successfully upgraded our website software which has given us the opportunity to modernise our website. We have increased our links to educational videos and research information and the vast majority of our content is available to everyone whether they are a member or not.

NZ Dystonia Patient Conference

Secretary/Treasurer Laraine flew to Christchurch at her own expense to attend this conference on the 17th June 2023. There were interesting presentations on dystonia and genetics, voice and swallowing issues, cerebral palsy/dystonia and spasmodic dysphonia. Laraine gave a presentation on

behalf of DNA where she spoke about the changes in our organisation, how we managed our move to online work, YouTube and Zoom, upgrading our website and current Australian research.

Members

We have increased the frequency of our member Zoom chats to monthly due to their popularity. We have also focused on building up the content in our members only section of the website. This includes encouraging use of our members forum (unfortunately with very limited success), providing written summaries of our Zoom chats and adding a Tips & Tricks section to help members navigate the health system. We also re-established our newsletter, the Dystonia Chronicle, which we aim to email out to our members bi-monthly. Back issues are saved in the members section of the website. Our membership currently stands at 283.

Plans for 23/24 financial year

Our plans include reviewing and updating the clinical information we provide with our advisory board to ensure it is up to date, relevant and accurate. Also to refine and expand the members' section of our website, consider possible grant opportunities, further develop our social media package and the allied health section of our website. These are in addition to our usual activities of member Zoom chats, working and liaising with other charities and organisations and activities for Dystonia Awareness Month.

Support

On behalf of the committee, I would like to thank all our members for their continued support of DNA. We've met so many wonderful members through Zoom chats, phone calls and emails and it is heartening to know that DNA is so valued. I sincerely thank the Ainsworth Family Foundation for their continued support and I also thank members and others who have made donations directly to DNA and through the PayPal Giving Fund. I would like to thank our advisory board for giving up their time to provide advice and guidance to the committee on clinical matters. Finally, I would like to acknowledge the work done by our volunteer committee who constantly make themselves available and whose work goes largely unnoticed. Our committee is made up of dedicated, passionate volunteers who do not seek accolades or recognition. They are committed to helping our members, advancing the interests of people with dystonia and making DNA a vibrant and successful organisation. I sincerely thank the members of the committee who have given me unwavering support in my role as President. It has been an absolute pleasure working with you all.

Due to the adoption of our new constitution with one year terms for committee members, we will be vacating our positions at this AGM and elections will take place for the coming year.

I wish you and your families and loved ones a happy and safe Christmas and New Year.



Warm Regards
Denise Duclos - President