

Dystonia Chronicle



Professor Lynley Bradnam, the Dystonia Awareness Seminar September 2016

We have lost our favourite Kiwi back to her homeland. We thank her for her amazing efforts for people with dystonia and her support of DNA, both as a DNA member and as part of our Advisory Board. We wish her well in her new endeavours. Read Margot's tribute to Lynley on Page 2.



Many registrants opted to stay in Hotel 179 prior to the Dystonia Awareness Seminar and joined together along with a few local DNA members for a pre-seminar dinner – a great time was had by all!



From left to right: Doctor Neil Mahant, Associate Professor Victor Fung, Professor George Mellick, Question Time, Dystonia Awareness Seminar 29 September 2017

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Professor Lynley Bradnam and her advancement of understanding of dystonia

I first met Lynley at a time when my cervical dystonia had become more severe, and involved strong head turns to the left, right and back. I was desperate for hope and treatment options, and was referred to the neuro-physiotherapist and academic James McLoughlin. James mentioned that another physiotherapy academic at Flinders University was looking for dystonia study participants. It was so exciting to hear that dystonia research was happening in my own city of Adelaide, and I jumped at the chance.

When I met Lynley the researcher, I was struck by the deep and genuine concern that she showed towards the suffering of people with dystonia.

Over time, I was involved in a number of her trials, testing the benefits of transcranial magnetic and direct current stimulation as novel treatments. I experienced notable periods of switching off of dystonic activity during the trials, particularly during an extended six-month trial. This was a very memorable experience, and gave me much-needed hope.

Another benefit of the studies was the chance for Lynley to introduce me to study participant, Sylvia. This was the first person with dystonia I had met face to face. I was very moved. It actually changed my life, to feel I wasn't alone, and was an important step in my journey of becoming more accepting and comfortable with my own identity as a person with dystonia.

Further research with Lynley followed, including a kinesiophobia scale (fear of movement), and investigations into vision-related quality of life; working memory and laterality recognition; and balance, stepping reactions and gait, as Lynley learnt from us the challenges of living with dystonia that extend well beyond the dystonic muscle activity.

I so much enjoyed getting to know Lynley as a very lovely person. It was sad, then, when

Lynley moved to Sydney to take up the position of Head of Discipline (Physiotherapy) at the University of Technology (UTS), but what an opportunity for her to continue dystonia research in a larger international hub. It was clear that the benefits would increase even more.

Along with her continued research studies and publications, Lynley started moves towards a movement disorders clinic at UTS.

Her videos and photos of study participants are now being used in lectures on dystonia, which she introduced into university curriculums in Australia.

She has also been active as a member of the DNA Advisory Board, giving input to the development of brochures on dystonia, and as a member of the Australian Dystonia Support Group, clarifying the dense language of research studies for us.

She presented on her research at a number of events, including the Parkinson's Australia National Conference in 2015, which included a dystonia stream, and which she helped us to organise. She helped in so many ways to bring us all together.

Now that Lynley is heading back to New Zealand, there will be a huge loss felt. The legacy of her research and activities to date will clearly live on and continue to benefit us greatly.

Thank you, Lynley, from the bottom of our hearts, from all the dystonia community in Australia. We loved having you here. It was a great privilege.

Margot Chiverton

Tips about deep Brain Stimulation (DBS)

DBS is not a surgery to be taken lightly and it's normally not suggested to you until you have exhausted all other avenues. But once you have done your research and decided to go forward and spoken at length to your Neurologist or Neurosurgeon, my advice is STOP researching because you can drive yourself crazy with worry. You are in good

hands let them lead you through the process.

Remember DBS is not a cure and if the transmitter stops for any reason the symptoms come back within minutes. So, look after your equipment. If you have a self - charging battery, get in to a habit of picking one or two days in the week to recharge. I normally come home from work get my tea and a cuppa, put the TV on and make myself comfortable. Then I set the charger going and just relax while it does its thing; the world can wait till it finishes.

It will take time to get your settings right, you must be patient and give feedback to your neurologist or nurse. Keeping a diary is always a good way to remember your progress. I found a few weeks after the surgery I developed tingling in my scalp near the surgery scars, but this is just the nerve endings rejoining and it will go, so don't panic.

Some people may develop some discomfort near the transmitter. I didn't, but I was told if it happened it wouldn't last long and would go soon afterwards.

If you need dental work done you need to take antibiotics before the procedure, so speak to the dentist or your GP for a script before the procedure.

After I had my transmitter replaced it was put lower in my breast, so I can no longer have a mammogram on that side. Now I have a mammogram on the other side and an ultrasound on both breasts

I recently had surgery on my stomach and as they were going to use diathermy it was important that the surgeon talked to my neurologist and Medtronic. They were excellent and provided the surgeon with all the literature he needed before going forward with surgery.

When you go through the airport you need to show your Medtronic card. They have never actually looked at it. I usually hold it up and point to my chest and they think I have a pacemaker - it's easier that way than to go through the neurotransmitter tale. Then they will pull you aside and pat you down. You can choose to go to a room, but I've never done that. They are very good about it all even in the USA it was not a problem. Remember your charging equipment does not come out of your baggage allowance.

After DBS no more jumping out of planes or any activity that could pull and damage your cables. Luckily, I'm a chicken so haven't had this problem. NO hair dye/colouring can be used until 6 weeks after surgery. I know I drove my Neurologist crazy over this one, he just didn't get it, but I had to cover those grey hairs coming through and if they shave your head the hair doesn't come back curly -which disappointed me.

If you have problems with your equipment contact Medtronic straight away; they give great customer service and any equipment that has broken for me has been replaced the next day or they have offered to meet me to fix the problem.

Robyn McIlvar

A few words from the President

A very warm welcome to all especially our new members I hope you enjoy reading about DNA's many highlights over the past year. We have started another busy year with a letter to the NDIS regarding the process of acceptance of dystonia as a recognized neurological condition that can cause serious disability. Another matter on this year's agenda is Dystonia Awareness month/week/day we will be taking this to the appropriate government authorities.

Regards, Kerrie Jackson

New Zealand Seminar

Kerrie Jackson & Juliette Walker travelled to New Zealand in June 2017 to represent DNA at the New Zealand Dystonia Patient Network (NZDPN) Meeting. This report was written by Juliette & Kerrie.



We continue to strengthen our alliance with the New Zealand Dystonia Patient Network (NZDPN). Both Juliette Walker and Kerrie Jackson attended, by invitation, the NZDPN Conference which was held this year in Auckland. We were both warmly welcomed by the New Zealanders. Their recent newsletter link is attached, which outlines some of the presentations:

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

On Saturday morning Dr Bren Dorman gave an in- depth lecture on the treatment of laryngeal dystonia which he treats, in partnership with the neurologists at Auckland Hospital, with Botox. There were

several his patients present and they seemed very happy with his care. Dr Lynley Bradnam gave a talk on neuroscience and its application to dystonia.

After lunch Sandra Palmer, a clinical Psychologist, gave an excellent talk on mindfulness and self-care and its usefulness in chronic illness and pain.

Mark Dromgoole talked on the advantages of a good web page and social media. Mark also suffers from dystonia and shared how he copes with its idiosyncrasies.

David Barton, a member of the NZDPN committee had attended a conference in the USA and gave a report on the National Spasmodic Dysphonia Association's recent symposium.

Kerrie Jackson gave a very professional report on DNA with its major focus on information and the care taken to provide it correctly. As part of her presentation, she put forward on behalf of DNA the importance of our ties with NZDPN, Blepharospasm Australia and other Dystonia Groups in Australia to work together for a Dystonia Awareness Day/Week or Month. Hopefully the awareness event will take place in September 2018 after the appropriate government authorities have been approached.

On the Saturday night, many of the participants attended a dinner and enjoyed exchanging their stories.

Juliette Walker / Kerrie Jackson

Movement Disorder Society of Australia & New Zealand

Laraine and Kerrie travelled to the Gold Coast for the Movement Disorder Society of Australia and New Zealand's Annual Scientific Meeting where we were kindly given a booth for DNA by the organiser, Rebecca Fielding.



Gold Coast

This was a great way for DNA to become known to all the Movement Disorder Specialists, particularly the soon-to-be Movement Disorder Specialists, the Specialist Nurses and Allied Health registrants. We also met up with all the other companies / booth holders who are involved with Dystonia.

Dystonia Awareness Seminar 2017



Kerrie & Laraine with Doctor Neil Mahant, Professor Victor Fung & Professor George Mellick after the Q&A Session.

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 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 also 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 have been 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. Our thanks also 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.



Our VIC & NZ Registrants
L – Heather Smith
R – Jayne Lewington Lovell



Collages of the Seminar ⇅



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Dystonia Network of Australia (DNA)

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Kerrie Jackson	President
Robyn McIlvar	Treasurer
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Sylvia May	Committee Member
Karyn Morgan	Committee Member
Cheryl Smith	Committee Member

Disclaimer:

The opinions given in this newsletter are not necessarily those of DNA

Laraine McAnally

Editor