

# Dystonia Chronicle

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### In Memoriam

This edition of the Dystonia Chronicle is dedicated to Phil Mangan, Robyn Mcllvar's brother, who was the DNA Secretary from the beginning of DNA for two years before he remarried and relocated to the USA. Phil died suddenly on 27 August aged just 56. Our thoughts are with his wife, his children, Robyn and her family.

### The Health Report on Dystonia

Jake Morcam contacted us with a request to ask our members if some of them would like to take part in the above report. From the list of willing members, two of our members were contacted for interviews. Robyn Mcllvar and Paul Ainsworth. Jake also contacted Associate Professor Victor Fung, Associate Professor Stephen Tisch and Professor Lynley Bradnam for their input. The result was an excellent broadcast of the Health Report showcasing Dystonia. The ABC also managed to have it ready to air for Dystonia Awareness week. If you want to listen to the broadcast again the link is on our web site – [www.dystonia.org.au](http://www.dystonia.org.au) media, then press releases.



Robyn Mcllvar with Jake Morcam at the taping

### Dystonia Awareness Week 7-14 September 2019

This year we again had two dystonia awareness days at major Sydney Hospitals, St Vincent's Hospital and Royal North Shore Hospital. If you would like to hold one of these days in 2020 please contact us and we will supply brochures etc.



Kerrie Jackson and Denise Duclos at North Shore Hospital's Dystonia Awareness Day



**Juliette, Robyn & Kerrie at ST Vincent's Hospital Dystonia Awareness Day.**

In the lead up to Dystonia Awareness week we had a 30 second professional radio ad produced by Grainger Films and distributed by Livermore media free of charge. In addition, Grainger Films did not take any fee for the ad and voice over and we are now one of the charities they support. Our sincere thanks to these companies.

We will alert the members as soon as we have secured the dystonia awareness day for 2020.

**DNA Seminar in Adelaide 21 September 2018 by Margot Chiverton**

On a Friday in September, a day-long Seminar was held in Adelaide, during Dystonia Awareness Week. Speakers were varied and included: neurologist Dr James Temlett speaking on treatment of focal dystonia, particularly botulinum toxin ; podiatrist Jodie Simon talking about how cervical dystonia affects walking and what can assist; Dr Lynley Bradnam talking about her research on gait and balance in dystonia and also Transcranial Magnetic Stimulation as a novel treatment; occupational therapist and nutritionist Elizabeth Barnard helping us to conserve our energy to make it through the day; ophthalmologist Dr Sumu Simon talking about blepharospasm; nurse Emily Wang educating us on empowering ways to approach pain management; and blepharospasm sufferer Naomi Thredgold sharing her journey with blepharospasm with much humour.

Margot Chiverton provided ideas for apps and online programs to help with living with dystonia, including sleep assistance, relaxation, pain management,

balance, retraining your brain, and recording your symptoms. She also shared information on the many dystonia support groups around Australia.

There were brochures and information handouts from Dystonia Network of Australia, Australian Dystonia Support Group, Blepharospasm Australia, Australian Dysphonia Network and pharmaceutical companies.

The seminar was organised by the Dystonia Network of Australia Inc. with Margot providing the organisation in Adelaide. Blepharospasm Australia also assisted in sourcing a speaker.

On the day a very enthusiastic and supportive crowd of seven people attended to hear the speakers.

The speakers were very sincere and giving, as well as knowledgeable, and this was reflected in the excellent feedback received after the event via feedback forms. The attendance number was unfortunately low, and reasons given for not attending included difficulty staying at an event for a whole day due to dystonia symptoms, health issues and transport issues. For some, paying for attendance was difficult, although concessions and free tickets were also available.

Those who attended enjoyed warm camaraderie and were able to exchange stories and gain new understanding from hearing others' experiences. The whole day (apart from Emily Wang's presentation) was videoed and is now available on the DNA website. Hopefully the video will be of great benefit to those who were unable to attend in person.

There was further fellowship enjoyed the night before the seminar at a seminar dinner at the event venue, the Adina Apartment Hotel.

The seminar ended with a screening of the short film Dystonia, by Peter Chiverton, which aims to spread awareness of dystonia in the form of an emotional drama about the true story of Margot Chiverton, who was forced to give up music due to dystonia. There were a few tears afterwards and recognition of shared experiences in dealing with such a difficult condition in our lives.

Kind thanks to Dystonia Network of Australia for enabling this event to occur for the Adelaide audience and for the wider audience who will view the video.

## A few words from the President

2019 has been another busy year for DNA as you will see from the newsletter articles. What you don't see is the work that goes on behind the scenes: the preparation and postage of membership packages and mail outs to neurologists and allied health: the email responses and telephone query replies : ensuring we fulfil our responsibilities to the governing bodies such as Fair Trading, the ACNC (Charities Board) fundraising authorities and the ATO: the web site upkeep and updating: the organisation and attendance at relevant seminars and conferences.

DNA as always is run by a small group of volunteers who give up their time to ensure the organisation keeps going. We have had some financial setbacks over the past 12-18 months, but I am delighted to inform you that we have been given a \$20,000 anonymous donation to assist us to run DNA while we look at other more sustainable avenues of income. We ask members to bring their ideas on this subject to the table.

Our thanks go to the Ainsworth Family Foundation for their donation, Elly Bath for her initiative to have friends donate to DNA via Pay pal giving fund in lieu of birthday presents and the other anonymous donors via this fund.

Lastly, as you will all be aware the very deserving Australian of the Year, Doctor James Muecke, an ophthalmologist whose amazing work here in Australia and overseas has been recognised and rewarded, has focal dystonia. Doctor Muecke also devotes days every week to the charity ***Sight For All***.

We intend to contact Doctor Muecke to request that he mentions dystonia wherever possible in any of his future interviews as he did in the ABC radio interview.

Best wishes for 2020 to all our members and their families

Kerrie Jackson  
DNA President

## New Zealand Seminar

This year Laraine and Robyn travelled to New Zealand in June 2019 to represent DNA at the New Zealand Dystonia Patient Network (NZDPN) Seminar.

The NZDPN put on an excellent meeting on 16 June 2019 in Rotorua both in the topics and the presentations. We were made very welcome by everyone and enjoyed the friendly atmosphere as well as the wealth of information. Particular mention here to David Barton, Alison Fitzpatrick, Jayne Lewington Lovell and the NZDPN committee.

I'm sure Robyn would agree that the Seminar Dinner needs a very special mention- yum!



## NZDPN Seminar Dinner

### Highlights:

**Doctor Mark Simpson**, Professor of Clinical Neurology at Auckland, gave a very interesting brief history on Dystonia and the treatments through the ages. From being touted as physiological, then unfortunately for some time regarded widely as a psychiatric condition, until around 3-4 decades ago with treatment options opening up. He also spoke about the genetic types of dystonia and how many more genes have been discovered since DYT1 in 1997.

He emphasized how complex and individual dystonia is and that it is crucial to assess the individual carefully in order to advise on appropriate treatments which means more understanding by, and education of, health professionals.

**Doctor Chris Lynch**, Clinical Director, Midlands Botulinum Toxin Clinic, talked about his many years in the botulinum clinics and how the clinics had

evolved over the years with considerable, continued input from all levels of staff and also patients to make the whole process more user-friendly and less clinical. A team approach within the clinics with close follow-up worked well.

Chris also has a passion for training medical officers and leads an Annual Botulinum Toxin teaching clinic where a team approach includes neurologists and trainees who discuss and treat patients.

**Professor Lynley Bradnam, physiotherapist and neuroscientist**, spoke eloquently about research studies on the non-motor symptoms associated with dystonia including depression, anxiety, pain and fatigue and how these impacted on quality of life, often more than the physical symptoms of many types of dystonia. Fatigue being the most troublesome and acting, with the other motor and non-motor symptoms, as barriers to exercise.

Lynley, in her present research study, spoke about early findings in her research pointing to fatigue and pain being the most common barriers. Also, that low impact exercises such as stretching, walking and yoga were better tolerated than high intensity exercise. The research study continues.

The speakers were all extremely engaging and knowledgeable

### **ANZAN (Australian and New Zealand Association of Neurologists) Scientific Meeting**

Kerrie, Laraine & Robyn manned the booth at the above meeting. We met up with neurologists from our advisory board, general neurologists, trainee neurologists, other charities and pharmaceutical reps. We made some new contacts and as a result posted out brochure packs and were added to other neurology web sites around Australia.

### **GP Training Days Sydney & Adelaide 2019**

Both days were very successful with many enquiries from GPs and requests for DNA brochure packages.



**Kerrie & Laraine at the Sydney GP Training Day**



**Margot Chiverton, who was responsible for organising the booths for GP Training Day, manning the DNA Adelaide booth.**

### **CC-DR Meeting May 2019**



The above photograph was taken at the Inaugural APON (Australian Patient Organisation Network) in Sydney in May 2019. DNA was one of the health charities invited by CC-DR to take part in this event. CC-DR's vision is: "... to facilitate meaningful

connection between service providers, research organisations, the non-profit sector, practitioners, industry, government and the communities for which they provide a service or aim to benefit.” APON was established to bring health charities together for networking, mentoring and collaboration to improve health pathways for patients. We will keep you up to date with developments

**Hilary Nourse**, one of our members had Deep Brain Stimulation last year. She has been blogging about her experiences. If you would like to follow Hilary, this is her link:

<https://dbssurgery-apatientsthoughts.blogspot.com/>

### **The importance of rehabilitation in the treatment of cervical dystonia**

Viewpoint by Matthieu, a 38-year-old person with cervical dystonia living in Paris, France.

February 7, 2019

Working as a teacher and a tour guide in Paris, I was diagnosed in September 2017 with cervical dystonia, one month after my first symptoms had started to appear. I first realised something was going on while performing a guided tour of an exhibition in Paris: I remember how my neck muscles had suddenly and quite unexpectedly become very tense during the tour and how my head would oddly be forced to move slowly yet almost irrepressibly to one side. I also realised a few days later that something was not right either when walking or sitting in a public place, and even more so when talking to someone. After typing my exact symptoms on the internet, I came upon the words “cervical dystonia” and “spasmodic torticollis”. By the end of September, I had an appointment with a neurologist who luckily happened to be specialised in movement disorders. I explained to her how I had been feeling over the past month and after assessing my movements and posture she rapidly confirmed that I had cervical dystonia. Shortly after, I was to receive my first botulinum toxin injections, a treatment which I am still undergoing.

In my case, the diagnosis came as a real shock. At first, I was often left wondering how this could have happened. Had I brought my cervical dystonia on myself after years of stress, notably due to the

fact that I had chosen to resume my studies at a postgraduate and doctoral level, while carrying out several professions at the same time? I also recall how during the summer of 2017 I had experienced a kind of burnout due to the unusually large number of guided tours I had conducted.

I initially believed I could more or less manage to conceal my symptoms, but as my dystonia took root, I began to realise this would be increasingly difficult to achieve. I thus felt the need to wear almost constantly during the day a scarf tightly wrapped around my neck, which also provided some though very limited comfort as it would somewhat help me relax my head and neck while standing or walking. In addition to that, I remember how I regularly had to use the “sensory trick” and how I had to correct my posture almost constantly throughout the day. My symptoms soon became almost impossible to manage, notably when doing my guided tours, as I would only have approximately 10 seconds to deliver my commentaries, before having to use the “sensory trick” to retrieve a less uncomfortable position of the head...

For months, I had often been looking for some kind of external help that would allow me to be less bothered during the day by my dystonia. Indeed, it seems that patients with dystonia are often led to seek greater comfort and to find solutions such as sensory tricks that will make their symptoms easier to bear. In retrospect, I believe one should try to seek a balance between comfort and rehabilitation: too much comfort and one often forgets about the necessity to make progress in relearning the normal use of the cervical muscles; too much focus on rehabilitation and one can be led to think too much about one’s dystonia, to the detriment of one’s own comfort and quality of life. It should be stressed, however, that a properly carried out rehabilitation programme can also lead the patient to feel greater comfort and serenity, in that, by relearning to better control the head and neck movements and to maintain a more natural posture, the patient can eventually improve his or her quality of life.

Emphasis should therefore be placed on the importance of rehabilitation in the treatment of cervical dystonia. After the first series of injections I received in November 2017, I noticed some limited improvement, but I believe in retrospect that it was really the combination of well-targeted botulinum toxin injections and repeatedly executed, precisely carried out corrective movements, which played a key role in my rehabilitation. Since I have right torticollis, coupled with left laterocollis and some

retrocollis as well – I later found out that I am also doing some “lateral shift” -, I did not exactly know at the beginning where or how I should start my rehabilitation programme. Together with my physical therapist who was trained according to Dr Jean-Pierre Bleton’s method for rehabilitation of cervical dystonia, I first worked on correcting the most obvious abnormal movement, which in my case was the rotation of the head to the right side. After three months of daily exercises repeated many times throughout the day during short sessions, and which consisted in turning the head to the opposite side of the dystonia and in maintaining for a while the corrective position of the head, I realised that it had become easier for me to place the head in a position closer to the central axis. Once I had passed this first stage, during which the patient is encouraged to relearn the proper activation of the corrective muscles – those which are often insufficiently working in the case of people affected by cervical dystonia -, Jean-Pierre Bleton, whom I had first seen in December 2017 at the Rothschild Foundation Hospital in Paris, recommended that I move on to different exercises in my rehabilitation programme. Since I had managed to regain strength in the antagonistic muscles – those which should oppose the dystonia -, I now had to relearn to achieve proper motor control, particularly when turning my head to the side of my dystonia. Over the following months, I thus practiced at home two different exercises: the first one consisted in slowly carrying out full-range rotations, from right to left and left to right, with a pause on the midline, while the second one relied on the use of proprioception: I was advised to try to place the head correctly along the midline before a mirror with my eyes closed, and then to open my eyes again to check that the head was well-positioned.

During the first few months after my symptoms had begun to appear, my quality of life had significantly deteriorated: I was almost incapable of standing, walking, talking to people, or going to a public place without my symptoms becoming more acute. But thanks to the treatment, I have managed to “integrate” the dystonia into my daily life, to tame it so to speak, thus making life much easier for me now than it was at the beginning. In this respect, doing the exercises in front of a mirror was key in my rehabilitation. I would say that there are two reasons for this: first, it allows you to confront your own reflection in the mirror, which is often an issue for patients with cervical dystonia. For months, I had been dealing with the problem of other people’s gaze directed towards me, and this would often make the dystonia even more difficult to control. But I realised that I also had difficulty

keeping my head straight while looking at myself in the mirror. In allowing you to better face up to your own image, doing the exercises in front of a mirror can therefore make it easier for you to confront people’s gaze, even to the point where you start feeling it is no longer so much of a bother to you. The other reason why using a mirror can also be of great help to patients is because it enables them to make sure they are doing the exercises correctly. Sometimes you think you are doing the exercises in the right way or you think your posture is straight, while in fact this is not the case. Thanks to the rehabilitation programme I have undergone for the past year and a half, I can now walk straight again, and I can stand and sit next to people and talk to them without any obvious symptoms becoming apparent.

In a nutshell, it is to be emphasised how the patient should be led to find within himself or herself the resources which may allow him or her to improve. While well-targeted botulinum toxin injections remain a treatment of choice, rehabilitation can also play a key part in the improvement of one’s symptoms, as its goal is to gradually allow the patient to relearn the correct and spontaneous use of the cervical muscles in an autonomous manner.

**If you would like to tell your story in the newsletter, please contact us.**

**Disclaimer:**

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

If you have specific questions about your dystonia, please direct them to your neurologist. Information in this newsletter is of a general nature only.

Laraine McAnally

Editor

## **Dystonia Associations & Support Groups:**

### **Dystonia Network of Australia (DNA)**

Kerrie Jackson & Laraine McAnally

9 Denman Parade, Leura NSW 2780

Tel/Fax: 02 47843368 or Kerrie's mobile:

0414648571

Email: [info@dystonia.org.au](mailto:info@dystonia.org.au)

Website: [www.dystonia.org.au](http://www.dystonia.org.au)

Australia's National Blepharospasm Support Organisation:

### **Blepharospasm Australia Inc.**

5 Fenton Place, Bouvard, WA 6211

Lyn Smith

Mobile: 0408 485 751

Email: [secretary@beb.org.au](mailto:secretary@beb.org.au)

[chairman@beb.org.au](mailto:chairman@beb.org.au)

Website: <https://beb.org.au>

### **Australia Dystonia Support Group (ADSG)**

Lee Pagan

Email: [ADSG@live.com.au](mailto:ADSG@live.com.au)

Website:  
[www.australiandystoniasupportgroup.wordpress.com](http://www.australiandystoniasupportgroup.wordpress.com)

### **Australian Dysphonia Network (ADN)**

Louise Mayer

Email: [australiandysphonianetwork@gmail.com](mailto:australiandysphonianetwork@gmail.com)

Website: [australiandysphonianetwork.org](http://australiandysphonianetwork.org)

## **NSW**

### **Blue Mountains & Greater Sydney Dystonia Support Group (BM&GSDSG)**

Meets bi-monthly – same contact details as DNA

### **NSW Blepharospasm Support (BEB)**

Stephen Bradley

Mobile: 0408 232 338

Email: [stevebrad60@gmail.com](mailto:stevebrad60@gmail.com)

<https://beb.org.au/support/support-in-new-south-wales>

### **Newcastle & Hunter District Dystonia Support Group**

Elly Bath

Mobile: 0411 252 110

Email: [ellybath@gmail.com](mailto:ellybath@gmail.com)

## **ACT**

### **ACT & Surrounding Districts Dystonia Support Group**

Kerrie Jackson

Contact details as per DNA

## **QLD**

### **QLD Blepharospasm Support (BEB)**

Grant Rutherford

Email: [granrutherford46@gmail.com](mailto:granrutherford46@gmail.com)

Website: <https://beb.org.au/support/support-in-queensland>

### **North Queensland Dystonia Support**

Suzanne Bayliss

Tel: 07 4032 4033

Email: [s.l.bayliss@bigpond.com](mailto:s.l.bayliss@bigpond.com)

## **VIC**

### **VIC Blepharospasm support Group (BEB)**

Website:

<https://beb.org.au/support/support-in-victoria>

## **SA**

### **Blepharospasm Support (BEB)**

Website:

<https://beb.org.au/support/support-in-south-australia>

### **South Australia Dystonia Group**

Jacqueline Jeremy

Email: [sadystonia@gmail.com](mailto:sadystonia@gmail.com)

## **WA**

### **BEB Western Australia Support Group Inc.**

Lyn Smith

Mobile: 0408 485 751

Email:

[secretary@beb.org.au](mailto:secretary@beb.org.au)

Website:

<https://beb.org.au/support/support-in-western-australia>

## **NT**

### **NT Blepharospasm Support (BEB)**

Carrol

Email: [gandcalynch@gmail.com](mailto:gandcalynch@gmail.com)

Website:

<https://beb.org.au/support/support-in-northern-territory>

### **DNA Committee:**

Kerrie Jackson	President
Denise Duclos	Vice-President
Robyn McIlvar	Treasurer
Laraine McAnally	Public Officer / Secretary
Anne Cooper	Committee member