

# Dystonia Chronicle

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Anne Cooper and Chris Gavenlock who joined Kerrie Jackson and Laraine McAnally at the Westmead Dystonia Awareness Day

## In Memoriam

This edition of the Dystonia Chronicle is dedicated to Les Mangan, Robyn McIlvar's father, who attended many DNA meetings, and who died on the eve of this year's DNA Seminar. Robyn has been our Treasurer since the beginning of DNA and Les was very dear to his family. He will be long remembered by the committee for his warm personality and good humour. Les was 90 years' young.

## Dystonia Awareness Week 14-21 September 2018

As well as the Sydney and Adelaide Seminars, for the first Government Calendar Dystonia Awareness Week, DNA had 2 Dystonia Awareness Days at 2 major Sydney hospitals, Westmead Hospital and St Vincent's Hospital.



Kerrie Jackson & Jayne Lewington Lovell at the Mezzanine Level of St Vincent's Hospital for the Dystonia Awareness Day



Kerrie Jackson & Laraine McAnally at St Vincent's.

### Sydney Dystonia Awareness Seminar

This year's seminar was held in collaboration with the Department of Neurology, at the Education Centre, Westmead Hospital. Despite a very slow registration we had a very successful day with excellent speakers that agreed to be videotaped and will soon be able to be viewed on our web site. Contact us for more information.



Donna Galea from Neurology assisting with registration.

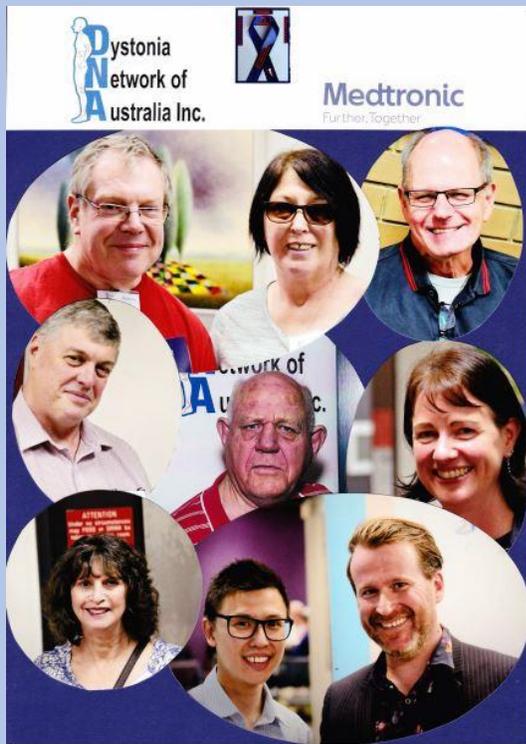
### Some of our Speakers



First row from left: Doctor Jacqui McMasters, David Tsui, Doctor Bart Post  
 Second row: Laraine McAnally, Doctor Stephen Tisch, Kerrie Jackson  
 Third row: Doctor Hugo Morales Briceno, Melani Boyce, Emma Etheringham



Jayne Lewington – Lovell & Chris Gavenlock  
 Jayne spoke about the New Zealand Dystonia Patient Network (NZDPN) & Chris the Australian Dystonia Support Group (ADSG)



Some of our Registrants: ^ v



## Final Seminar Program

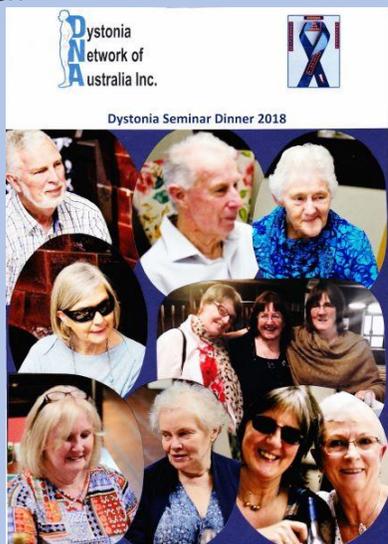
0830-0930	Registration & Refreshments
0930-0940	Welcome, Housekeeping & Acknowledgement of Sponsor
0940-1010	Doctor Stephen Tisch, Specialist Neurologist, St Vincent's Hospital, Sydney – Non-invasive Treatment for Tremor
1010-1040	Doctor Jacqueline McMaster, Neurosurgeon, Westmead Hospital, Sydney - Deep Brain Stimulation (DBS)
1040-1100	Emma Everingham, Practitioner Movement Disorders, Westmead Hospital – Follow up for Patients Post DBS
1100-1130	Catered Morning Tea
1130-1200	Melani Boyce, Senior Neurological Physiotherapist, Westmead Hospital, Sydney - Update on Physiotherapy in Dystonia
1200-1230	Doctor Bart Post, Visiting Neurologist from the Netherlands – How is Dystonia Diagnosed?
1230-1300	Doctor Hugo Morales Briceno - Showcasing Young-onset Dystonia
1300-1315	Jayne Lovell - New Zealand Dystonia Patient Network
1315-1415	Catered Lunch
1415-1450	Dystonia organisations in Australia – DNA / AD SG / ADN / BEB /
1450-1515	First Sydney Screening of Peter Chiverton's short film "Dystonia"
1515-1525	Closing of Seminar - Thanks to Speakers, Sponsor & Registrants
1525-1600	Catered Afternoon Tea



Our thanks to **Medtronic** for their ongoing sponsorship of our Sydney seminar and to **Diane Collington** from Medtronic who attended the Medtronic Booth on the day and to David Tsui, Donna Galea & Jane Griffith from the Department of Neurology for their valuable assistance.

Also, our thanks go once again to **Peter Jackson** who has been our photographer for all our Sydney seminars and pre-seminar dinners and who always manages to capture the ambience of the day.

Many of the registrants stayed at Hotel 175 again this year, where we held the pre-seminar dinner.



**There will be a short report on the Adelaide Dystonia Seminar in the next newsletter.**

### **A few words from the President**

2018 has been another successful year for DNA. We continued our work in raising awareness of Dystonia and the organisation is now advertised by many more movement disorder specialists which results in more visits to the web site [www.dystonia.org.au](http://www.dystonia.org.au)

I quoted the figures for the DNA web site in the 2017-2018 financial year president's report, but this figure has almost doubled in the last 90 days with 3,709 users and almost 13,000 pages viewed. I urge you to go to our web site regularly for updates and links on our media news and press release pages.

Membership is growing steadily and now stands at 160. DNA remains solely run by volunteers with only a few people involved in the running of the organization. Our growth and legal requirements depend on these people who devote many, many hours of their time. We would really appreciate more involvement from other members as there are many things that could be done online which would leave us free to attend to the more formal side of the organization.

A big "thank you" must go to our Advisory Board who provide us with their expertise and are extremely generous with their time and are always willing to answer general questions sent to us from both our members and non-members.

As DNA is the National Charity for all Dystonias we made an application to the Australian Health Department for a national dystonia awareness week. This was granted and is now on the [health.gov.au](http://health.gov.au) web site for all Australians

who suffer from Dystonia. The week requested and granted is September 14-21 inclusive. We are still hoping that New Zealand will join us soon.

Our 10<sup>th</sup> brochure, written by Doctor Stephen Tisch, "Tremor in Dystonia" is now available on our web site with some information sheets on the rarer forms of dystonia coming soon.

**A New Wollongong Dystonia Support Group** is going to be set up and for those wishing to be part of this group please contact Kerrie: Mobile: 0414 648 571 or Email: [info@dystonia.org.au](mailto:info@dystonia.org.au) for more details. **Please Note:** You do not need to be a member of DNA to be part of this group. It is open to all who need support for dystonia and would like to have a coffee and a chat in the Wollongong and surrounding areas. Contact details will remain in Professor Carmody's Botox clinic. We are hoping the Support Group will start early next year.

On behalf of our committee and members I want to sincerely thank the following generous people and companies for their kind donations to DNA this year: Macquarie Bank for Brad Coleman / Paul Ainsworth Family Foundation / Medtronic grant for our 2017 Seminar. Also, thanks to Merz Pharmaceuticals who have once again donated 100 translated copies of Jean-Pierre Bleton's book for physiotherapists: – Spasmodic Torticollis – A Physiotherapy Handbook

I would like to close by wishing all our members and their families a very Merry Christmas and a safe and Happy New Year.

Warm Regards

Kerrie Jackson DNA President.

### **New Zealand Seminar**

This year Laraine McAnally travelled to New Zealand in June 2018 to represent DNA at the

New Zealand Dystonia Patient Network (NZDPN) Meeting. This report was written by Laraine.

The NZDPN put on an excellent meeting on 16 June 2018 in Auckland both in the topics and the presentations. I was made very welcome by everyone and enjoyed the friendly atmosphere as well as the wealth of information.



**Doctor Barry Snow**, the first speaker and a renowned movement disorder neurologist, gave such an exceptional talk on dystonia, taking a very complex subject and splitting it up into digestible building blocks for the registrants, that I felt I had to attempt to write it in full. Any errors are mine.

Doctor Snow, despite being on call for neurology and the hospital, delivered his presentation in a very relaxed, comfortable style. He began with the meaning of the word dystonia - abnormal tone, and spoke of the neurologist, Oppenheimer, who first described it and gave the name of musculorum deformis to the genetic form now known as DYT1, a generalized form of childhood dystonia found most commonly in Ashkenazi Jews. Doctor Snow explained that dystonia could be a general symptom of other conditions or a neurological diagnosis in the subset of neurology called the movement disorders,

manifesting in distorted postures, tremor and fixed or repetitive abnormal movements. He described dystonia as a software problem of the brain and although the basal ganglia (BG) at the base of the brain is known to be involved in dystonia, it is a network problem involving other areas of the brain and the pathways to and from the BG including the cortex and the cerebellum which are all involved in coordination of movement.

Doctor Snow introduced the concept of learned motor functions on the cortex of the brain that then are relayed to the basal ganglia and become automatic e.g. walking. The basal ganglia do this by closing off other circuits that are not required and isolating areas for function. For example, if you want to move a finger the influence of the BG inhibits the adjacent fingers moving too (surround inhibition). If there is a glitch anywhere in the network the motor message goes awry. In dystonia, however, there is no surround inhibition but an overflow which is a distinctive part of dystonic response which he likened to a fight between the normal muscle tone and dystonic tone and so the software is corrupted. In dystonia after stroke there is a delay before the symptoms appear and this is because the dystonia is not a direct result of the actual lesion from the stroke but because it interferes with the circuitry. He described how in dystonia there is too much going on but in the area in the lesion caused by the stroke there is nothing going on.

The majority of brain scans are normal in dystonia and he explained this is because it is a software not a hardware problem – dystonia is the wrong way to do things but exactly why this happens is not fully understood. Doctor Snow spoke of occupational dystonia where there are repetitive movements such as in musician's dystonia or writer's cramp. The person often tries to use the other hand but over time with

repetition again the BG learns the wrong way to do it and the other hand is affected. The types of dystonia were discussed, and he reported that dystonia is often categorized into generalized dystonia, hemi-dystonia where there is usually a brain lesion of some kind responsible, segmental dystonia such as Meige's syndrome with facial/oral dystonia and blepharospasm so more than one area affected and lastly focal dystonia including task-specific dystonia. He also mentioned that in generalized dystonia which is almost always early onset that the dystonia usually begins in a leg and gradually spreads to other areas. In focal dystonias, which are the most common type and occur in the 5<sup>th</sup>, 6<sup>th</sup> and 7<sup>th</sup> decade mainly, there is a low incidence of spread to other areas this might be related to the more mature brain.

Doctor Snow spoke of dystonias that almost always have a genetic cause such as generalized dystonia in the young, myoclonic dystonia characterized by sudden jerks of the limbs and 'whispering dystonia', a type of familial spasmodic dysphonia causing a whispery voice. He also touched on secondary dystonia where the cause is known and induced by stroke, hypoxic brain damage or a lesion where the network of coordinated movement is damaged. He also suggested that idiopathic dystonia, a dystonia where the cause is unknown, may well have a genetic basis. On the subject of genes Doctor Snow told us that our genes are not nearly as large as first thought – we have 26,000 genes in our genome, but the networks are all talking to each other so the amount of connections in the networks are far greater. Some genes make us susceptible to certain conditions. We may inherit fair skin, so we are more susceptible to skin cancers, but we don't have the actual gene for skin cancer and if we stayed out of the sun may never get it! In this way our genes can tip the balance of possibility. In dystonia confused messages that go back to the brain are in a feedback cycle or loop which

then affects the joints and tendons and our proprioception, where we feel parts of our body are in space, is malfunctioning. Sometimes when botulinum toxin is injected into the dystonic muscle that is driving the abnormal posture the network wiring is reset for a time and the dystonia normalizes.

When treating dystonia, it is important to exclude the obvious other conditions that may have different treatment options such as Wilson's disease where there is difficulty excreting copper and it builds up in certain areas of the body including the brain or dopa-responsive dystonia who respond really well to dopamine medications (the same medications given to people with Parkinson's disease). Since the cause is rarely found for most dystonias, then the neurologist must deal with the symptoms as there is no known cure. Management can include medications – anticholinergics such as Artane or a group of drugs that are fairly toxic that probably rebalance the networks but unfortunately have a lot of side effects, so few people continue with them.

Doctor Snow spoke about botulinum toxin as the drug mostly used in dystonia which is also very effective. Botulinum toxin releases the tight muscles and weakens overactive muscles and around 75% of people gain good benefit. He told the group that the old type of surgery in cervical dystonia where individual muscles were cut was not effective as the BG found another muscle to cause the problem and you could not continue to cut neck muscles. He also spoke of the benefit of the toxin wearing off as then the BG did not have enough time to disrupt the network using another muscle to cause the abnormality. He also explained that muscles that were required for complex fine movement did not do so well with the injections as they became weaker. However, not everyone responds to either medications or botulinum

toxin so for a small percentage of people with dystonia Deep Brain Stimulation (DBS) is an option. Doctor Snow explained that DBS acts like a stroke, interrupts and turns off the circuitry in the flawed network causing the dystonia. It takes some months for the benefit to be seen so patience is required.

Doctor Snow also answered questions:

1. In response to a question on the new treatment for tremor called MRI guided focused ultrasound (MRgFUS) and if this could be used for dystonia. Doctor Snow discussed the treatment where high frequency MRI-directed ultrasound beams travel through the scalp and skull directly into the exact part of the brain (the thalamus) to create a small lesion which blocks the tremor but said he was not sure if it would work for dystonia.
2. Asked about the role of medicinal cannabis in dystonia Doctor Snow was not against the idea but felt that the research was patchy and poor, so the benefit is still unclear. Therefore, good research is now required.
3. A question of the use of second skin in dystonia brought concerns again about the lack of evidence but Doctor Snow said the concept made sense with regard to sensory input in dystonia and since there were no side effects felt this was an intervention worth a trial. Julie Rope, neuro-physiotherapist, added that she was already using a similar treatment and having good success.
4. Doctor Snow was also questioned about Vitamin D for dystonia. He said people had to be careful as evidence of its use in dystonia is not proven and side effects prove it is not always safe to take supplements unless under the care of your treating neurologist.

**Alison Fitzpatrick**, Chair of NZDPN, who had been allocated secretary and the keeper of Doctor Snow's phones during the presentation, warmly thanked Doctor Snow for his excellent presentation.

**Alison** also gave a very interesting presentation to the group about her experiences with "Be-Leadership" a programme under the umbrella of the "Be.Accessible" movement unique to New Zealand which aims to allow all New Zealanders access to reach their full potential regardless of disability. The leadership programme runs over 12 months and the challenges are to encourage a more accessible society for personal and societal growth, pushing through barriers and encouraging different perspectives on "disability, accessibility & possibility".

**Julie Rope** is an experienced neuro-physiotherapist who also happens to be a member of DNA. She is the Director & Senior Clinical Practitioner in Neuro-rehabilitation and now also with the Duncan Foundation – see link below:

<https://duncanfoundation.org/about-us/history-of-duncan-foundation/>

Julie is a trustee and Head Clinical Manager with the Duncan Foundation and gave a very interesting talk explaining her role of educator and expert clinician, with the foundation which is supporting people with neuromuscular conditions, including dystonia, by establishing clinics for assessment, rehabilitation, management and education by trained multidisciplinary teams in at present three areas in New Zealand. Julie is very passionate about the care of neurological patients. To find out more about her role you can also access information at [www.ropeneurorehab.co.nz](http://www.ropeneurorehab.co.nz)

Julie also spoke about techniques she trials with Dystonia patients and we are hoping to have

Julie present here in Sydney sometime in the near future.

**Linda Quimby**, one of our members and an artist, donated these 2 paintings to the Westmead Children's Hospital, where they hang at the entrance to the Neurophysiology Department's Treatment Room. Linda wrote "The process of making art is a very important one for me: it started a healing within that I didn't expect. I couldn't lift my arms up when I decided to paint again so I held the brush in my mouth, then I realised I am not going to accept this and by painting every day for weeks on end I gradually regained the use of my arms and fine motor movement. And I still paint every day, sometimes I am in a wheelchair now and I don't mind because at least I can paint."

**Linda Quimby**



The paintings are called "Touching Hearts"



One of Linda's recent paintings will be raffled in February 2019 to raise funds for DNA

## **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 – Tel: 08 9582 1676

Mobile: 0408 485 751

Email:

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

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

Website:

<https://blepharospasmaustralia.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)

[http://blepharospasmaustralia.org.au/support  
t-in-new-south-wales/](http://blepharospasmaustralia.org.au/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:

[http://blepharospasmaustralia.org.au/support  
t-in-queensland/](http://blepharospasmaustralia.org.au/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)**

Elizabeth Foster Tel: 03 9587 2326 Royal  
Victorian Eye Hospital

03 9929 8536 Fax: 03 9663 7203

Email: [efo33132@bigpond.net.au](mailto:efo33132@bigpond.net.au)

Website:

[http://blepharospasmaustralia.org.au/support  
t-in-victoria/](http://blepharospasmaustralia.org.au/support-in-victoria/)

## **SA**

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

John Yeudall

Mobile: 0419 045 698

Email:

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

Website:

[http://blepharospasmaustralia.org.au/support  
t-in-south-australia/](http://blepharospasmaustralia.org.au/support-in-south-australia/)

## **South Australia Dystonia Group**

Jacqueline Jeremy

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

## WA

### Blepharospasm Support (BEB)

John Yeudall

Mobile: 0419 045 698

Email:

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

Website:

<http://blepharospasmaustralia.org.au/website-help/>

### BEB Western Australia Support Group Inc.

Lyn Smith

Tel: 08 9582 16676

Mobile: 0408 485 751

Email:

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

Website:

<http://blepharospasmaustralia.org.au/support-in-western-australia/>

## NT

### NT Blepharospasm Support (BEB)

Carrol

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

Website:

<http://blepharospasmaustralia.org.au/support-in-northern-territory/>

## DNA Committee 2018-2020

Kerrie Jackson      President

Laraine McAnally      Public Officer &  
Interim Secretary

Robyn McIlvar      Treasurer

Denise Duclos      Committee Member

A vacancy exists for the position of Vice-President and for a position of committee member

### 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 and is not to be used in place of medical advice.

Laraine McAnally

Editor