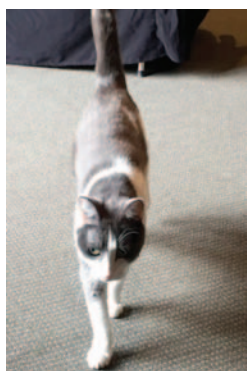


# News+Views

Newsletter 82 – July 2018

## 🐾 2018 NZDPN Seminar and AGM 🐾

On Saturday June 16th we were back at the Surrey Hotel in Auckland, for our annual Seminar and AGM. The Surrey cat (aka GM) oversaw the day's events and was most



vigilant with food quality control and ensuring our laps were warm.

It was an informative day with topics ranging from a medical perspective on dystonia, to ideas on managing everyday symptoms. There was also the chance to meet up with old friends and make new ones. We were delighted to host DNA leader Laraine McAnally,

and welcome back our cousins from the Essential Tremor group.

This year's evening meal was served in the Cornwall Room. Not only was the food delicious, but, being in a separate room made it easier to relax and talk freely with other dystonians.

Big thanks to all the speakers, who so generously shared their time and expertise with us. Special mention goes to Barry Snow who was on-call for Auckland Hospital; and Julie Rope dividing her day between our seminar and a fund-raising event for the Duncan Foundation.

### Highlights of Surrey Seminar

The programme included guest speakers with neurological and physiotherapy backgrounds; a representative from Be.Accessible, and a patient's perspective on living with Essential Tremor. Some of the items presented will be covered here, and, in the November newsletter.

This issue will include a review from guest speaker Dr Barry Snow; a summary of the panel discussion; and, a report from our Trans-Tasman friends at the DNA.

### Seminar Presentation – Dr. Barry Snow

We were very fortunate to have Dr Barry Snow speak to our group. Dr Snow was the senior specialist on call at Auckland Hospital on this particular day and he took a couple of urgent queries from his Registrar during the presentation. After nominating chair Alison Fitzpatrick as 'keeper' of the phone, Barry began with a brief background of dystonia.

#### ***This included;***

- the meaning of the word which is abnormal tone

- the neurologist Oppenheimer who first defined the condition
- dystonia is a movement disorder but can be a general symptom of other conditions

Barry went on to say dystonia can be thought of as a software problem in the brain. He gave the analogy of pitching a tent on your own where the guy ropes are your muscles. You pull a rope on one side of the tent and the other ropes do something strange. You run to the other side of the tent and adjust those ropes, and the original rope reacts in a strange way. And on it goes; this could be a model of dystonia.

Basically the dystonian brain has software issues in the basal ganglia, where 'learned' movement is

stored. While the basal ganglia is known to be involved in dystonia, the problem is within the network as other areas of the brain including the cortex and cerebellum are involved in the coordination of movement.

Barry spoke about the concept of learned motor functions on the cortex of the brain that are then 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.

An example of this is how the basal ganglia tell the thumb to twitch. It is like computer coding: First: turn on twitch thumb. Second: turn off twitch fingers and other thumb. In dystonia, this simple computer program is corrupted and surround inhibition is affected. This results in overflow movement, where the other fingers move in a disordered fashion. So, in other words, too much is happening in the brain.

One way of disrupting the cycle of confused messages is Botox injections to the affected muscles. They work by releasing the tight muscles and weakening overactive ones.

According to Dr Snow around 75% of people gain good benefit by regular Botox treatment. This is because the network wiring is reset for a time and the dystonia normalises.

***There is no cure for dystonia at present but management strategies include;***

- botulinum toxin
- dopamine for dopa-responsive dystonia



- anticholinergics such as Artane
- Deep Brain Stimulation

An issue that is arising in Barry's clinics is that of medical marijuana. Barry was willing to address this very openly with us. Research and scientific understanding about cannabis and the benefits (or otherwise) for people with movement disorders is still fairly new and there is not much data available yet. So much of what we are hearing is anecdotal. Dr Snow advises caution at this stage, but it is very much a case of "wait and see".

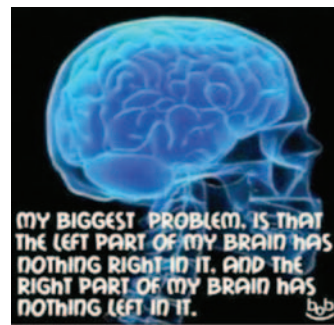
When questioned about Vitamin D for dystonia. Barry said people had to be careful, as evidence of its use in dystonia is not proven, and that research shows it is not always safe to take supplements unless under the care of your treating neurologist.

### Living With Dystonia: What Works For You

The panel discussion led by David Barton, Desiree Sargon and Jayne Lewington Lovell, resulted in a variety of coping strategies in living with dystonia. Within the group, ideas ranged from using a neck pillow whilst driving, to writing with fingerless gloves on. In addition, here are resources from members who couldn't attend the seminar but wanted to share what works for them.

- Choose words carefully and write instead of speaking
- Tell people about your condition
- Techniques that include saying mantras, counting and mindfulness exercises
- Community Occupational Therapists have been good support for some members
- Check if you are eligible for a Disability Allowance. The Benefit Education Trust was recommended for further information
- Two short Ted talks that discuss dystonia  
<https://www.youtube.com/watch?v=DwkHK3rfK00>  
<https://www.youtube.com/watch?v=czW-xBvDtHY>
- Herbal patches called Salonpas, available from Asian markets or acupuncture clinics. Helpful for aching neck, back and shoulders
- The Lightning Process; a tool to help keep in balance. Knowledge gained about the mind/body link is used for relaxation and control of the body. Originator Phil Parker has written several books and spoke on radio when visiting New Zealand last year. <http://www.radiolive.co.nz/home/audio/2017/09/well-being-through-how-your-brain-connects-to-your-body.html>
- 'Daytime Revive and Sleep' drops available at pharmacies
- Biopton light used for pain relief; you focus the light on the problem area. It comes with books on how to use it. Contact is Mirjana Arlov Ph: 09 422 2096 or <http://www.bioptron.com/>
- Lean against walls, or any solid object to support your neck and back
- Have a reversing camera in your car
- Shakti Mat; this mat can be rolled up for the neck or laid flat on the floor. It works on acupressure points for relaxation and pain relief

- And last but by no means least, do things that make you laugh. Laughter as they say is the best medicine...



### Dystonia Network of Australia - Laraine McAnally

As Public Officer & Interim Secretary, Laraine gave an update on the Dystonia Network of Australia Inc. She spoke about their aims, which mirror those of the NZDPN group, and how they are achieved.



Alison Fitzpatrick & Laraine McAnally

#### ***They include;***

- the production of their information brochures, made with assistance of their multidisciplinary advisory board
- hosting yearly seminars with presentations from experts in the field of dystonia
- attending events like the Movement Disorder Scientific Meeting on the Gold Coast in 2017

The purpose of attending these meetings is to introduce DNA to new movement disorder registrars, specialist nurses and allied health attendees; and to strengthen connections with Australian movement disorder neurologists.

Laraine also spoke about their seminars being held during Australian Dystonia Awareness Week. The DNA has managed to secure from 14-21 September in the government calendar, and seminars will take place in both Sydney and Adelaide. Unfortunately they were unable to include New Zealand in the application, but, would like to see the NZDPN apply for the same week for dystonia awareness then we could have an Australasian Dystonia Awareness Week!

DNA now has 135 members and 24 Advisory Board members. All the Committee including office bearers are volunteers. They do not discriminate between members and non-members when people ask for information regarding support groups, brochures to increase awareness of dystonia or advice



regarding movement disorder neurologists in their state. If they are seeking general advice about any aspect of dystonia their query is referred to the advisory board anonymously and DNA relay the replies to them.

Finally, Laraine acknowledged the value of our alliance, and thanked the NZDPN warmly for inviting her to our seminar to speak about DNA's current status.

#### **Save the Date**

Dystonia Network of Australia Inc.  
4th Dystonia Awareness Seminar

Where: Westmead Hospital, Westmead NSW 2145

When: 0900-1600 hours Friday 14 September 2018

Proposed programme includes Sydney Premiere of the short film "Dystonia"

<https://www.dystonia.org.au>

#### **My life in film – DYSTONIA**

Australian musician Margot Chiverton tells her story:



On 5 June, close to 100 people attended the Mercury Cinema in Adelaide to watch the premiere of a short film called Dystonia. The film, made by my husband, Peter Chiverton, portrays my story of giving up a classical music career due to the onset of dystonia, and dealing with the aftermath. What a lovely husband I have to make a film about my experience, a tribute to the journey I've been through, and through this helping to raise awareness of dystonia.

It was a little confronting to see my difficult story portrayed on the screen, but I was able to manage that by thinking about how it will benefit people with dystonia around the world.

Peter plans to use the film as a 'proof of concept' for a feature film. There has been strong interest from producers in Australia and overseas. They are keen to see a short film, like Dystonia, first, to help them decide whether to go ahead with the feature.

Peter is now working on getting the film seen more widely and getting a producer on board for the feature, and hopefully raising lots of dystonia awareness along the way. As dystonia is not well known, I hope that this film will be a help in changing that.

As far as we know, this is the first drama about dystonia in the world. There have been documentaries, but no dramas that we know of. Hopefully the launch of this short film will lead to the first feature film drama about dystonia.

You can watch the trailer at this link:

<https://www.youtube.com/watch?v=95hfnDzcA3s>

#### **Brain Day**

This is a community expo with approximately forty stands, including ours, representing various neurological and other brain disorders. Cuzzie Steven Fischer from the Essential Tremor group and Julie of RopeNeuro will also be there.

#### **Find a doctor**

We have been collecting info from doctors who have said they are happy to be listed on the Network's website. The following movement disorder specialists (doctors/medical practices/clinics) offer diagnosis, advice and treatment of dystonia.

##### *Auckland*

###### **Dr Rakesh Patel**

Auckland Medical Specialists

183 Gillies Avenue

Epsom 1023

Ph: (09) 638 9945

Specialty: Childhood dystonia and paediatric conditions

Referral: via a GP

##### *Paediatric Neurology*

Starship Children's Hospital

Park Road

Grafton

Ph: (09) 379 7440

[www.starship.org.nz](http://www.starship.org.nz)

Specialty: Childhood dystonia and paediatric conditions

##### *Dr Mark Simpson*

Auckland Medical Specialists

183 Gillies Avenue

Epsom 1023

Ph: (09) 638 9945

Specialties: Generalised dystonia, Focal hand dystonia (writer's cramp), Blepharospasm, Meige syndrome, Cervical dystonia (spasmodic torticollis), Hemi-dystonia

Referral: via a GP

##### *Hamilton*

###### **Dr Chris Lynch**

Midland Neurology & EMG Ltd Medical Specialists

3 Thackeray St

Hamilton 3204

Ph: (07) 957 4924

Specialties: Generalised dystonia, Focal hand dystonia (writer's cramp), Blepharospasm, Meige syndrome, Cervical dystonia (spasmodic torticollis), Laryngeal dystonia (spasmodic dysphonia), Hemi-dystonia

Referral: via a GP

*Disclaimer: the listing is provided as a service to those with an interest in dystonia and does not constitute a recommendation or endorsement by the NZ Dystonia Patient Network.*

Brain Day details:

Saturday 21st July • 9am-3.30pm

University of Auckland Business School

Owen G Glenn Building, 12 Grafton Rd, Auckland

<https://brainweek.co.nz/events/brain-day-auckland-2018/>

## Online Support Group

Evelyn Watson in Gore, Southland has a support group on Facebook. From Evelyn: "we welcome any new members and their families as we share the same interest ... our health!"

### **Evelyn's contact details:**

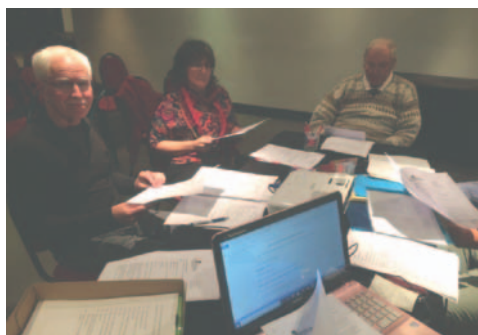
Phone: 03 208 5120 or 027 308 6305

Email: [watsayou@xtra.co.nz](mailto:watsayou@xtra.co.nz)

## Area Contact People

We are happy to welcome new Area Contact Person, Phillipa Norman. She is from the Rotorua area and has cervical dystonia. Folk like Phillipa perform a valuable service and are there to provide the all-important reassurance you are not alone. NZDPN welcomes volunteers for this role.

## Governance of the NZDPN



*From left to right:  
Dave Mitchell,  
Jayne Lewington Lovell  
& Roger Terry*

The Executive Committee is elected each year at the Annual General Meeting. Joining the line-up is Dave Mitchell (pictured above). Welcome to the team Dave.

The Committee for 2018/ 2019 are;

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Jayne Lewington Lovell, Roger Terry,  
Dave Mitchell

Network Manager: Philippa Hooper

NZDPN phone number: (06) 364 7618

NZDPN email: [info@dystonia.org.nz](mailto:info@dystonia.org.nz)

## From the Chair

Kia ora everyone! I hope you are managing to stay warm now that winter is upon us. It was lovely to meet so many of you during our recent seminar in Auckland. Thank you for supporting our network.

## Readers' comments welcome

We invite comments from our membership on how best we can serve you with any suggestions on how we could improve upon what we currently publish.

## Donations and membership

The NZDPN is a Health Promotion Association registered with the New Zealand Charities Commission (Registration: CC10565). As well as encouraging research into dystonia and promoting awareness of our condition, our mission is to provide information and support to all those affected by dystonia.

We are a 'grass-roots' organisation. Most of our leaders have dystonia themselves, and we are entirely reliant on donations, membership contributions and other charitable grants.

The Network invoices members once each year, in February, for the Annual Subscription. Membership is \$30 per annum and applies to the calendar year in which the payment is made.

Receipts are issued for amounts of \$100 and over, and otherwise on request. Any donations are tax deductible because of the Network's status as a registered charity. The Treasurer will issue donors with an official receipt which can be submitted to the IRD at the end of the Financial Year.

Internet Banking details are:

NZ DYSTONIA NETWORK

ANZ BANK, WAIKANAE

06-0577-0110415-00

Please complete the 'Code', 'Reference' and/or 'Particulars' fields to let us know your name, and whether a deposit is a donation or membership.

If you prefer to send a cheque our address is: The Treasurer, NZDPN, PO Box 34 259, Birkenhead, Auckland 0746

### **Mission Statement: Our 3-fold mission is:**

- To support dystonia patients with information, advice and networking opportunities
- To increase awareness about dystonia - both among the medical community and the public
- to encourage and facilitate research, with the aim of seeking better treatments, prevention, a cure

### *Disclaimer*

*Nothing in this newsletter is intended to serve as medical advice on dystonia. The NZDPN recommends that you consult your own doctor(s) and other health professional(s) regarding your diagnosis and treatment.*

We acknowledge and thank the New Zealand Lotteries Grants Board and Allergan for their financial support, and NZ Post for assisting by providing pre-paid envelopes under the Community Post programme.

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