

News+Views

Newsletter 85 – August 2019

2019 NZDPN Seminar and AGM



NZDPN members at the seminar dinner function

On Saturday June 8th we were at the Sudima Hotel in Rotorua, for our annual Seminar and AGM. The day was a busy one with a lot of information to take in. But as you can see in the picture above, we also had time to relax and enjoy ourselves. It is always good to have a record of these events and luckily Bruce Norman was on hand to take photos of the evening – nice one Bruce.

Greetings from the Chair: Alison Fitzpatrick

Mid-winter greetings to you all; our seminar in Rotorua was a great success - wonderful speakers, a superb venue plus the fellowship and support of other dystonians. All of this made for a memorable weekend. Thank you all for your support! After the seminar, I had the privilege of speaking at the NZ Essential Tremor support group's seminar, which was held a week after ours. I talked about what it was like to grow up with tremor and dystonia, and the similarities and differences between them. It is great to have such a good relationship between our two groups - we truly are neurological cousins.

Highlights of the Rotorua Seminar

In this edition items will include presentations from Dr Lynley Bradnam and Laraine McAnally of DNA; an update of the NZDPN website; and a review of David Barton's trip to the National Spasmodic Dysphonia Association conference in Boston.

Seminar Presentation – Dr Lynley Bradnam

As a neuroscientist and physiotherapist, Lynley utilises experience from both of these fields in research projects. Her presentation 'looking at non-motor symptoms in dystonia and barriers to physical activities' focuses on the impact of wider physical and psychological functions. This focus is an important one, as traditionally studies have only addressed motor symptoms, (with most treatment targeted at these impairments).

Lynley began by introducing a number of studies that identified non-motor symptoms. Common symptoms included;

- depression
- anxiety
- self-efficacy
- fear of movement
- worse quality of sleep
- pain
- fatigue

Researchers found that overall, non-motor symptoms contributed to both greater disability and reduced quality of life. Of these, fatigue was found to be the most burdensome and disturbing in a range of dystonia types.

These results are borne out by early findings of a physical activity study that Lynley is heading. While both motor and non-motor symptoms can act as barriers to exercise; pain and fatigue were cited as being the most common.

Participants also reported that lower intensity exercise, such as walking, Pilates, yoga and general stretching did not aggravate their dystonia. This is helpful information for researchers like Lynley, who are interested in how living with dystonia impacts on function and participation so better treatments and management strategies can be devised.



Seminar Presentation – Laraine McAnally



Laraine began by thanking the NZDPN for inviting her and Robyn McIvor to the seminar, stating how much the DNA values our alliance.

She then went on to outline initiatives that are part of what the DNA terms as 'Planning and Putting Dystonia on the Map'. These include events scheduled for their awareness week which runs from 7th – 14th of September;

- a Tele Health webinar
- education days at two local hospitals
- promotional radio advertising

Also hoped to coincide with awareness week is a slot on an ABC Radio programme – The Health Report. DNA members will be featured on the show talking about their experiences of dystonia. For updates and information; www.dystonia.org.au

Alison Fitzpatrick - the new NZDPN website

Alison has taken on the role of webmistress and is enjoying the digital challenge. Recent changes to the website are that it;

- has been simplified so that it aligns with our organisational aims and values
- is mobile-responsive
- is search-engine-optimised
- can be expanded at any time in the future

Check it out at: www.dystonia.org.nz

David Barton - 2019 NSDA Symposium

In May this year David visited the historic Fenway Park in Boston, to watch the 2018 World Series Champions Boston Red Sox, playing baseball. He also found time to look in at the National Spasmodic Dysphonia Association symposium and attended several speaker presentations and research workshops. The workshops were opportunities to interact with those working on discovering the causes and possible treatments of SD.

Three of these developments are;

- 1) German scientist Jürgen Konczak has developed a neuromodulation device that vibrates the larynx. The effect is similar to a sensory trick; and it is worn externally like a collar which makes it easy for everyday use.
- 2) Dr Christopher Honey, who is based in Vancouver, performs surgery similar to Deep Brain stimulation (DBS). The intention is to treat the underlying neurological cause and let the muscles function normally.

3) Dr Michael Pitman of Columbia University NY, is testing a device adapted from a cochlear hearing implant. The implant delivers electrical stimulation to overactive muscle spindles. Results show that these spindles are reset during stimulation, and, when used for an hour can last up to five days.

With further investigation these innovations have the potential to offer alternative treatment options that can improve both the voice and the quality of life of patients with SD.

Matters arising from the AGM

- Next year's seminar will be in Wellington on Saturday 16th May.
- We have received \$11,000 for the middle year of the 3-year grant from Lotteries which allows the network to continue with our activities

Governance of the NZDPN



Clockwise: David Barton, Desiree Sargon, Jayne Lewington Lovell, Dave Mitchell & Alison Fitzpatrick

The Executive Committee is elected each year at the Annual General Meeting. The Committee for 2019/2020 are;

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

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

Network Manager: Philippa Hooper

NZDPN email: info@dystonia.org.nz

Request for Study Participants

Dr Lynley Bradnam and her team are looking for people with to take part in their latest Dystonia research study - can you help them?

If you have been diagnosed with cervical dystonia by a neurologist you may be eligible to participate in this study. You would need to attend the Health and Rehabilitation Clinic at the Newmarket campus of the University of Auckland for one single session of around 3 hours duration. For more information contact Lynley at: lynley.bradnam@auckland.ac.nz or Phone 64 9 373 7599 ext 84102.

Living with a complex medical condition: An invitation to participate in an online survey.

Wendy Wrapson and her research team at AUT are exploring the impact that having a complex medical condition has on social relationships, and invite you to complete a 20-30 minute anonymous online survey at <https://tinyurl.com/y3qyudks>

To qualify you will need to have seen at least two medical specialists in the last 5 years; be aged 18 to 65 years; and live in New Zealand.

If you prefer a paper copy of the survey, please contact Wendy Wrapson: wwrapson@aut.ac.nz
09 921 9999 ext 6136 / 021 02220307.

Thank you

The NZDPN is made up of people who are united by a common bond – dystonia. By working together we can achieve the aims of supporting each other and promoting awareness to the wider community. Listed below are some of those who keep our group going; their contributions are greatly appreciated by the network.

- Jeremy Collinge, who prepares our accounts
- Mike Brabant at Big Red Design for the layout and printing of our newsletter
- Alex Tate who picks up and posts them
- Seminar speakers that give so generously of their time and expertise
- Dave Mitchell for organising and manning the stand at Auckland Brain Days
- Mark Dromgoole in updating our website
- Our cuddies at the ET group
- Australian connection with the DNA team
- And last but by no means least a big shout out to our Area Contact People;

Location (North to South)

Kaitaia

Janice Foster: Phone (09) 408 1369

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Cromwell

Alex Tate: alexmorva@slingshot.co.nz

Types of Dystonia

Blepharospasm

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Barbara Hampton: barbsie98@hotmail.com

Generalised Dystonia

Kath Chave: albatrosskc@gmail.com

Hemifacial Spasm

Jacqui Higgins: jghiggins@xtra.co.nz

Oromandibular Dystonia

Elizabeth McPherson: elizmcpherson@hotmail.com

Spasmodic Dysphonia

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Jayne Lewington Lovell: jllovell@gmail.com

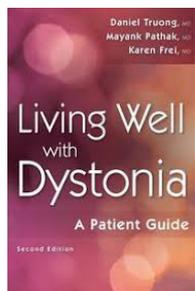
Book Review:

'Living Well with Dystonia: A Patient Guide'

by Daniel Truong, Mayank Pathak and Karen Frei

(Reviewed by Jayne Lewington Lovell)

I have a copy of this book at home which means I can go to it whenever the need arises. This updated second edition is written by three specialist neurologists with significant contributions from dystonia patients.



It is a mix of approaches that works well and includes a glossary of dystonia related terms from Abductor - Zyprexa. I find this list comes in handy when I want to know what health professionals are talking about. Also useful is the overview in Chapter 2 as it covers diagnosis and treatment.

I like the description of how the brain works (or doesn't in dystonia), complete with helpful drawings.

Some dystonian tips on living well;

- Take time to research and find out who in your area treats your disorder
- Accept your diagnosis and adjust your life appropriately, life goes on after diagnosis
- Seek out a support group
- Learn to pace yourself
- Go out in public and do the things you enjoy; being active is important both mentally and physically

My final words come from the Spasmodic Torticollis Association; **'Remember... You Are Not Alone.'**

Rare Disorders NZ: Share your experience

Would you or someone you know would be interested in sharing your story of living with a rare disease? We want to keep the pressure on the government to address the barriers for people with rare diseases, including medicines access, and make sure the focus is not just on patients with cancer. If you are interested, our Communications Manager Amy would interview you initially by phone or email and then create a press release for you to sign off. Amy would then send it to journalists we have relationships with and hopefully one of them would like to speak with you, as well as take a photo. She would support you throughout the process and ensure your story was told compassionately and accurately. If you would like to share your story, please email Amy on; amy.watson@raredisorders.org.nz

We acknowledge and thank the New Zealand Lotteries Grants Board for their financial support.
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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. All 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.


New Zealand
Dystonia
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Email : info@dystonia.org.nz