

National and international news and views
Networking Dystonia patients



New Zealand
Dystonia
Patient Network Inc.

News+Views

Newsletter 84 – April 2019

Kia kaha Chch

15-03-2019

The NZDPN extends our deepest condolences to all those affected by the terrorist attacks on Friday March 15th in Christchurch. Our hearts go out to the families whose loved ones were killed and maimed at the Al Noor and Linwood Mosques.

To the fifty men, women and children who were slain in their place of worship – we honour your memory. To the forty-two more injured on that day; we send our best wishes in your recovery.

Greetings from the Chair: Alison Fitzpatrick

Kia ora - By the time this newsletter reaches you, preparations will be well underway for our seminar in Rotorua on Saturday 8 June. Whether you are newly diagnosed, still to be diagnosed or quite established in your diagnosis, you may still be seeking answers and suggestions for living your best life with Dystonia. Our seminars provide a great opportunity to meet up with like-minded folk and share stories and strategies. As far as strategies go, I have recently been focusing on my walking technique because I was finding that I was tripping over and injuring myself too often. I am literally learning to take things one step at a time. It is a humbling experience. I hope to see many of you in Rotorua.

Annual Seminar in Rotorua, 8th June 2019

The Network is pleased to announce that our 2019 Seminar and AGM are being held in the Sudima Hotel, Rotorua on Saturday 8th June. The function room at the Sudima is on ground level so suitable for wheelchair access if required. All members are invited to attend for a fun day of learning, networking and companionship, with partners, family and friends. The Seminar will be followed by the Annual General Meeting.

The Sudima Hotel offers accommodation. If you wish to stay on-site on the Friday and/or Saturday night please book directly with the hotel:

Tel: 0800 783 462 (toll-free) or +64 7 348 1174



Email: reservations@sudimarotorua.co.nz

Physical Address: 1000 Eruera Street, Rotorua

This year the Network is pleased to offer an accommodation supplement of \$125 per room to 2019 financial members (current as at 31 March), who have travelled from beyond Waikato and the Bay of Plenty. It can be for any hotel in Rotorua, if the Sudima is fully booked that weekend. To apply for reimbursement please submit your hotel receipt to the Network. This can be scanned and emailed to info@dystonia.org.nz or a copy posted to NZDPN, P O Box 34 259, Birkenhead, Auckland 0746. Payment will be made by cheque.

Registration Fee for attending the Seminar

Members: \$40.00 per person or \$70.00 per couple

Non-members: \$80.00 single or \$130.00 a couple.

Meals/ Food provided within Registration Fee:

Saturday – Morning Tea, Lunch, and Afternoon Tea

Other Meals:

Breakfast(s) and the Saturday evening meal (optional) are to be paid by attendees.

We would strongly encourage you to stay for the Saturday evening meal as this is an excellent opportunity to socialise with other dystonians.

If you are registering for the seminar please indicate whether you wish to join us for dinner. It will help us with planning if you pre-pay the cost of the evening meal of \$45 per person with your registration fee.

A registration form is included with this issue of the newsletter and can also be downloaded from www.dystonia.org.nz

We hope you can join us for this informative and supportive day where you can relax and share with others who genuinely understand what it means to have Dystonia.

Seminar Programme – Saturday June 8th 2019

This year's theme: 'You are not alone'

- 8.45 Registration - Tea/Coffee on arrival
9.15 Welcome and introduction of Executive Committee by Chair Alison Fitzpatrick
9.30 NZDPN Network Manager, Philippa Hooper will report on Network activities during the past year
9.35 Dr Mark Simpson - Dystonia – a medical perspective
10.40 Short Break
11.00 Dr Chris Lynch - Dystonia - What I learn from my patients
12.00 Medical panel - Questions and answers
12.30 Lunch
1.30 Dr Lynley Bradnam - Medical research, including Dystonia and Exercise
2.15 Alison Fitzpatrick - the new NZDPN website
2.30 Dystonia Network of Australia Inc.
2.45 David Barton - report on the 2019 NSDA Symposium
3.00 Patient perspectives
3.20 Evaluation of the day
3.25 Short Break
3.50 NZDPN Annual General Meeting

Note that the presenters are happy to take questions after their addresses, but please restrict these to general issues rather than your own diagnosis and treatment.

The programme is subject to confirmation and the times are approximate.

NZDPN Annual General Meeting

AGENDA

- Apologies
- Minutes of Previous AGM (16 June 2018)
- Financial Report
- Annual Report from Executive Committee
- Election of Officers
- General Business

Please note that all members are welcome to attend the AGM, but you need to be a financial member (already paid subscription in the 2019 calendar year) in order to vote.

Evening Programme

- 6.30 Dinner at Sudima Hotel (optional)

Speakers

Dr Mark Simpson

Mark is a neurologist at Auckland Hospital; where he works as a general neurologist. He did subspecialty training in movement disorders in Auckland, Melbourne, London and Toronto.



Dr Chris Lynch

Dr Lynch is the Clinical Director of the Neurology Department, Waikato Hospital. He is also in private practice as a neurologist at the Anglesea Clinic in Hamilton. His clinical practice includes EMG, and botulinum toxin therapy, nerve conduction studies, neuromuscular disease and neurophysiology. Chris graduated in 1987 from Otago Medical School. Further training took him to the Radcliffe Infirmary, Oxford, UK, and Peripheral Nerve and EMG Fellowships at the Mayo Clinic, Rochester.



Dr Lynley Bradnam

Associate Professor Lynley Bradnam joined the Department of Exercise Science at the University of Auckland, in 2018. She is a New Zealand registered physiotherapist who has held academic positions in Universities in New Zealand, United Kingdom and Australia since 1998. Lynley is interested in understanding the brain mechanisms causing Dystonia and how everyday functions are affected.



In her research the focus is on finding solutions to improve people's wellbeing and quality of life.

Update from Dr Lynley Bradnam

Thanks to the Network for inviting me to provide this update to my activities in Dystonia research. This month Distinguished Professor Sir Richard Faull invited me to join the Centre for Brain Research at the University of Auckland as a principal investigator. This is a great way to raise awareness of Dystonia amongst the scientific community and the University. By the time you read this, Brain Awareness Month will have come and gone; hopefully some of you were able to attend Brain Day and the great evening talks on offer at the University in March. In terms of our Dystonia research, we have completed

the internet survey on physical activity; thanks to all who contributed. We are now in the process of analysing this data, so watch this space. I am hoping to attend the International Movement Disorders conference in France in September this year to present the findings – a good advertisement for little old New Zealand!

We have applied for two funding grants to support new projects, one a brain research study and the other will look further at physical activity. Each of these studies is expected to take two years to complete. I also have two post-graduate students who will undertake another Dystonia study – so we are keeping busy! Many of you will be aware of Margot Chiverton, from the short film 'Dystonia' written and produced by her husband Peter. Margot and I have been collaborating for a number of years now. All my research proposals and grant applications are read by her and she gives me her 'living with Dystonia' perspective. This is very important to make sure our research is appropriate and relevant for people with Dystonia.

Finally, I am looking forward to speaking at the annual Network seminar in June and meeting lots of you. Please let me know what you think of the work – any new ideas are welcome!

Auckland Brain Day – 2019

This year's Brain Day had a change of venue from previous years, and was held at the University of Auckland, Faculty of Medical and Health Sciences. The day was well attended with full lectures and a range of short lectures. These community-based lectures are becoming very popular which we consider added to a good public presence.

Highlights amongst the community stands included the:

- very busy animal balloon makers
 - most melodious 'CeleBRation Choir'
 - working dogs for Epilepsy NZ
 - amazing gadget from RopeNeuro that assists with drop foot

As usual, our stand was next to our 'close cuddies', the Essential Tremor Support Group which works well for both of us as we are able to share information. From some of the enquiries it seems that Dystonia is still unknown to a lot of people. Hopefully we were able to enlighten those we spoke with and along with our pamphlets got the message of "what Dystonia is" out there. Thanks to Dave and Pam Mitchell who did a really great job of promoting Dystonia as well as giving members a chance to get together.

Funded assessment for People with Dystonia

The Duncan Foundation is a charitable organisation which supports therapy programmes for people with neurological conditions in New Zealand. They have, for the first time, offered to fund a limited number of assessments for those with a diagnosis of Dystonia or who are finding it challenging to have a physical assessment of their condition and relevant advice on exercise prescription. Following on from the assessment you may be provided with a follow-up and review session if required. Funding will be available for a limited time.

Who should apply?

Any person with a diagnosis of focal Dystonia who wants to be proactive about the options for physical management of their symptoms.

Criteria for applying

- Confirmed diagnosis of Dystonia
- No formal physical assessment for Dystonia physical management previously provided
- Proactive about managing the symptoms associated with their Dystonia

Funding will be given to people on a 'first come first served' basis to applicants who meet the above criteria.

How do I apply?

Contact Julie Rope on 021 753 279 or 09 623 8433 to schedule an assessment, to discuss availability and to schedule an appointment.

<https://duncanfoundation.org/>

<https://www.ropeneurorehab.co.nz/>

Book Review(s) – Shona Daube

(By Jayne Lewington Lovell)

'A funny thing happened on the way to the Neurologist' Pink Cottage Publishing; Carterton, New Zealand.

Shona Daube is a New Zealand writer who was diagnosed with Multiple Sclerosis in 2014. A funny thing happened ... is part of a fund-raiser for the Wellington MS Society. It is also a very humorous piece of writing about coming to grips with a life-redefining disease.

'Does my Bum look Big with this Stick?'

Pink Cottage Publishing; Carterton, New Zealand.

"This book is dedicated to anyone for whom illness or disability play a major role in their life. I hope that reading



this may give you a smile". The dedication of Shona's second book invites readers back into her world. A world where there are two choices; to live like a hermit or to be loud and proud. Shona chooses to be loud and proud which gives a unique perspective on coping with everyday life. Strategies shared include ways to deal with keeping upright, dropsy and the dreaded brain fog. As well as finding this information relevant to my everyday life, I enjoyed the concise way both books were written. The illustrations are great with just the right touch of irreverence to help get a very serious message across. Thanks Shona – your good yarns did give me a smile! If you'd also like something to smile about, Shona has some of 'Does my bum look big with this stick?' to give away. For a free copy contact Shona at: shonadaube@gmail.com

Dystonia Network of Australia



We are pleased to announce our Dystonia Awareness Week on the Government Calendar for 2019 is 20-27 September. During this week we hope to hold Dystonia Information Days in at least 2 Tertiary

Hospitals in Sydney, and host a phone-in forum with a movement disorder specialist. We have also been given the opportunity to boost community awareness by advertising DNA and explaining Dystonia in community media in the lead-up to Awareness Week. We will keep you informed of any other activities. We are aware that other groups follow the American Dystonia awareness model which is the whole of September and we are happy to support any events during this time.

Kerrie Jackson – President

Laraine McAnally - Public Officer

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

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

Governance of the NZDPN

The Executive Committee is elected each year at the AGM:

Chairperson: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

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

Network Manager: Philippa Hooper

NZDPN phone number: (06) 364 7618

NZDPN email: info@dystonia.org.nz

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.

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New Zealand
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