



News+Views

Newsletter 81 – April 2018

Annual Seminar in Auckland, 16 June 2018

The Network is pleased to announce that our 2018 Seminar is again being held at the Surrey Hotel, Grey Lynn, Auckland on Saturday 16 June 2018.



The Venue is the Cornwall Room, which is at ground level, so is 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 Surrey Hotel offers accommodation. If you wish to stay on-site on the Friday and/or Saturday night please book directly with the hotel:

Tel: (9) 378 9059 Fax: (9) 378 1464

Email: reservations@thesurreyhotel.co.nz

PHYSICAL ADDRESS

Surrey Hotel
465 Great North Road
Grey Lynn

Registration Fee for attending the Seminar

For members: \$40.00 per person or \$70.00 per couple
For non-members: \$80.00 per person or \$130.00 per 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 dystonia people.

The cost of the evening meal is \$40 per person and this

year will be held in the Cornwall Room. 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 include payment for dinner 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 16 2018

This year's theme: **Better Living with Dystonia**

- 9.00 Registration - Tea/Coffee on arrival
- 9.30 Welcome and introduction of Executive Committee by Chair Alison Fitzpatrick
- 9.35 NZDPN Network Manager, Philippa Hooper will report on Network activities during the past year
- 9.40 Dr Barry Snow - Dystonia - A medical perspective
- 10.40 Short Break
- 11.00 Alison Fitzpatrick - Disability, accessibility and possibility
- 11.30 Patient panel discussion: 'Better Living with Dystonia'
- 12.30 Lunch
- 1.30 Julie Rope - the Duncan Foundation
- 2.10 Report from Kerrie Jackson representing Dystonia Network of Australia Inc.
- 2.40 Essential Tremor - the Commonalities with Dystonia
- 3.10 Short Break

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

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



Annual General Meeting

3.30 Declare AGM open (we will then adjourn for afternoon tea)

AGENDA

- Apologies
- Minutes of Previous AGM (17 June 2017)
- Financial Report
- Annual Report from Executive Committee
- Election of Officers
- General Business

Note that all members are welcome to attend the AGM, but you need to be a financial member (paid subscription in the 2018 calendar year) in order to vote.

Evening Dinner

6.30 Buffet meal in the Cornwall Room

From the Chair

Autumn greetings everyone; I hope the first few months of the year have been kind to you all. Thank you to all of you who have paid your annual subscription to the network. We are extremely grateful for your support. As this newsletter goes to press, we are finalising arrangements for our annual seminar. The day looks as though it will be an interesting one - with plenty of opportunities to catch up with other network members as well as some great learning. We hope to see many of you on the day.

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.

Speakers



Dr Barry Snow

Dr Barry Snow is a leading neurologist specialising in movement disorders such as Dystonia. He is recognised internationally for his expertise in

the management of these disorders, and locally, he is a leading authority in patient care, advocacy and research. Dr Snow established the Auckland Movement Disorders Clinic in 1995 to lead a centralised structure of specialists so patient care and research efforts in New Zealand could be optimised.



Julie Rope

Julie Rope is Director & Senior Clinical Practitioner at Rope Neuro Rehabilitation. She has a passion for working with the neurological population and ensuring they have access to assessment and support wherever they live in New Zealand and sharing knowledge with other professionals about neurological

condition management. More recently Julie has taken on the role of Trustee and Head Clinical Manager with the Duncan Foundation, providing assessment clinics and resources alongside educational lectures on the assessment and management of Polio. She is excited about the prospect of facilitating access to rehabilitation options to those with other neuromuscular conditions.

The NZ Essential Tremor Support Group

<http://www.essentialtremor.org.nz/>

Our cousins in the Essential Tremor group are an organisation of about 250 members. They meet all over the country,



with the aim of sharing ideas and hints with other sufferers, their families, caregivers and medical professionals. The group will be represented by National Chairman Dr Steven Fischer.

Patient Discussion Panel

The panel this year will comprise of NZDPN Committee members to lead the discussion, but, the focus is on group sharing. Bring your queries, resources or handy hints along - as when it comes to living with dystonia we are all the experts.

Obituary – Kathleen (Kay) Rogers

In memory of Kay Rogers from Auckland; Kay passed away late last year after a long illness with multiple health prob-

lems which included dystonia. According to her family, Kay appreciated being part of our organisation as it made a big difference to her to know that others are affected by dystonia.

Report from Dystonia Australia

DNA President Kerrie Jackson reports that the recordings from their 2017 seminar have been edited, and will soon be available on their website. Our Aussie friends have also just put out their latest newsletter which is online at <https://www.dystonia.org.au/>



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: Jayne Lewington Lovell, Roger Terry

Network Manager: Philippa Hooper

NZDPN phone number: (06) 364 7618

NZDPN email: info@dystonia.org.nz

Find a doctor

One of the Network's projects for this year is to create a listing at our website of New Zealand movement disorder specialists who treat dystonia. We have written to all the New Zealand neurologists and a few other interested doctors and hospital clinics on our mailing list to seek expressions of interest.

Our prospective and current members commonly ask us "Who treats dystonia?" when making enquiries through our website, and in the past attendees at our annual seminars have asked for this information.

As a service to new and existing patients we plan to offer a directory of movement disorder specialists and other doctors who treat or consult on dystonia. This would be similar to those offered at our support partners' websites - e.g. <https://www.dystonia-foundation.org/living-with-dystonia/find-a-doctor>



A listing in our directory would not be an endorsement or recommendation of any particular consultation or treatment options, but rather could make it easier for patients to seek appropriate medical advice or investigate referral options. We are aware that most healthcare professionals are not well informed about dystonia, so it makes sense to give patients this information to speed up the diagnosis and treatment process. Many of us recall how challenging it was to eventually reach a healthcare professional who understood our condition.

How can you help? Check the listing when it goes up on our website, and let us know if your specialist is not listed. It could be that they have not been approached to participate, and we would then contact them.

We are confident that the Network offering this service will help many in the dystonia community. Our thanks go to David Barton for getting this initiative off the ground.

NZ Organisation for Rare Disorders (NZORD)

Rare Disease Day Symposium February 2018 (Report by Alison Fitzpatrick)

I was fortunate to be able to attend a Symposium held at Auckland Hospital to coincide with World Rare Disease Day in February. This day was run by the NZ Organisation for Rare Disorders (NZORD). Here are some of the things I learned on the day;

- NZORD is the umbrella group that provides patients and families with information, support and advocacy
- The organisation works with health care professionals, researchers and health planners to improve knowledge about rare diseases, improve clinical care and assist in getting

access to treatments

- A rare disease is broadly defined as being one which is either life-threatening or chronically debilitating, has a high level of complexity and has an estimated prevalence of less than 5 in 10,000.
- Dystonia fits into the category of "Rare Disorder"
- In NZ there are over 300,000 Rare Disease patients. 50% of these are children, of whom 30% will not live to see their 5th birthday

Common challenges faced by rare disease patients include misdiagnoses which result in treatment delays, limited access to treatment and lack of information for patients and healthcare professionals. On a national and political level, the challenges include the lack of a national policy for rare diseases and the lack of a national patient register. All of the above impacts on the funding available for medicines needed to treat these disorders.

NZORD is currently lobbying the government for the establishment of a national database in the hope that this will drive improvements in the treatment and care of rare disorder patients and ensure that resources will be allocated to where they are needed the most. NZORD is also pushing for the establishment of an Orphan Drugs Fund that will sit outside of Pharmac.

I really enjoyed the day. It gave me an opportunity to chat with other people and groups who are "in the same boat" as us Dystonians. The message coming through from the clinicians who spoke to us was quite clear:

- Don't give up when seeking treatments or solutions.
- Trust your body and your instincts; you are the expert on your own body.

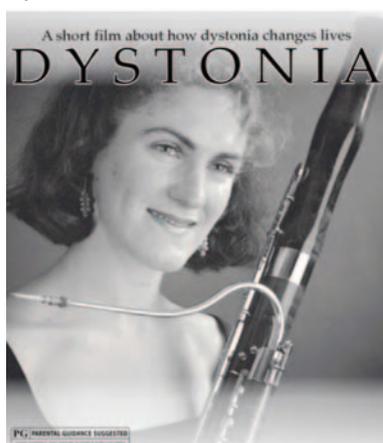
For more information: www.nzord.org.nz

My life in film – DYSTONIA

The story of Australian musician Margot Chiverton

It's an unusual experience to have a film made about oneself. But this is happening to me!

My husband has written a short drama about my story of being diagnosed with cervical dystonia and having to give up a deeply fulfilling and successful career as an orchestral musician in my mid-30s.



The film will be shown to film producers in Hollywood to encourage them to make the feature length film that my husband has written about my story.

The short version will also be distributed to help raise awareness of dystonia, and be entered into film festivals.

As film has such a high impact and the ability to reach far and wide, I believe this project will help many people who suffer from little-known conditions that often have a stigma attached to them and can alter a person's life dramatically. The name 'dystonia' will hopefully become much more widely known – how many people know this name already? It's a reality that people with dystonia live with daily; their

condition is unknown and unrecognised. And yet dystonia is the third most common movement disorder after Parkinson's disease and essential tremor.

The film is currently in post-production and we expect it to be released in the coming months. A whole new experience for me!
<https://pozible.com/project/dystonia-the-film>

Tips about Deep Brain Stimulation (DBS)

(From DNA Treasurer - Robyn McIlvar)

DBS is not a surgery to be taken lightly and it's normally not suggested to you until you have exhausted all other avenues. But once you have done your research and decided to go forward and spoken at length to your Neurologist or Neurosurgeon, my advice is STOP researching because you can drive yourself crazy with worry. You are in good hands; let them lead you through the process.

- Remember DBS is not a cure and if the transmitter stops for any reason the symptoms come back within minutes. So, look after your equipment. If you have a self-charging battery, get into a habit of picking one or two days in the week to recharge. I normally come home from work, get my tea and a cuppa, put the TV on and make myself comfortable. Then I set the charger going and just relax while it does its thing; the world can wait till it finishes.
- It will take time to get your settings right; you must be patient and give feedback to your neurologist or nurse. Keeping a diary is always a good way to remember your progress. I found a few weeks after the surgery I developed tingling in my scalp near the surgery scars, but this is just the nerve endings re-joining and it will go, so don't panic.
- Some people may develop some discomfort near the transmitter. I didn't, but I was told if it happened it wouldn't last long and would go soon afterwards.
- If you need dental work done you need to take antibiotics before the procedure, so speak to the dentist or your GP for a script before the procedure.
- After I had my transmitter replaced it was put lower in my breast, so I can no longer have a mammogram on that side. Now I have a mammogram on the other side and an ultrasound on both breasts.
- I recently had surgery on my stomach and as they were going to use diathermy it was important that the surgeon talked to my neurologist and Medtronic. They were excellent and provided the surgeon with all the literature he needed before going forward with surgery.
- When you go through the airport you need to show your Medtronic card. They have never actually looked at it. I usually hold it up and point to my chest and they think I have a pacemaker - it's easier that way than to go through the neurotransmitter tale. Then they will pull you aside and pat you down. You can choose to go to a room, but I've never done that. They are very good about it all - even in the USA it was not a problem.
- Remember your charging equipment does not come out of your baggage allowance.
- After DBS no more jumping out of planes or any activity that could pull and damage your cables. Luckily, I'm a chicken so haven't had this problem.
- NO hair dye/colouring can be used until 6 weeks after surgery. I know I drove my Neurologist crazy over this one, he just didn't get it, but I had to cover those grey hairs coming through and if they shave your head the hair doesn't come back curly - which disappointed me.
- If you have problems with your equipment contact Medtronic straight away; they give great customer service and any equipment that has broken for me has been replaced the next day or they have offered to meet me to fix the problem.

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, WAIKANA
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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New Zealand
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