

News+Views

Newsletter 78 – April 2017

2017 Seminar

The Network is pleased to announce that our annual Seminar and AGM will be held at the Surrey Hotel, Grey Lynn, Auckland on Saturday 17 June 2017.



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: \$30.00 per person or \$50.00 per couple

For non-members: \$70.00 per person or \$90.00 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 \$36 per person and we have asked the hotel to seat our group in a separate 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.

Programme for NZDPN Seminar - Saturday 17 June 2017

- 9.15 Registration - Tea/Coffee on arrival
- 9.45 Welcome and introduction of Executive Committee members by NZDPN Chairperson Alison Fitzpatrick
- 9.50 NZDPN Network Manager, Philippa Hooper will report on Network activities during the past year.
- 10.00 Address by Dr Lynley Bradnam
- 11.15 Short Break
- 11.30 Address by Sandra Palmer (Clinical Psychologist with expertise in movement therapy, pain and depression)
- 12.30 Lunch
- 1.30 Report from Dystonia Australia
- 1.45 Mark Dromgoole (social media and dystonia, including our new website launch)
- 2.15 David Barton (a report on the NSDA Conference in Nashville, TN held in May 2017)
- 2.30 Patient panel discussion - 'Coping - What helps my dystonia?'

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

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



Annual General Meeting - Agenda

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

- Apologies
- Minutes of Previous AGM (8 May 2016)
- 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 2017 calendar year) in order to vote.

6.30 Dinner at Surrey Hotel (optional)

Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting:

Chairperson: Alison Fitzpatrick

Deputy Chairperson: Barbara Hampton

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Pauline Granich, Jayne Lewington Lovell, Roger Terry

Network Manager: Philippa Hooper

NZDPN phone number: (06) 364 7618

NZDPN email: info@dystonia.org.nz

Speakers

Dr Lynley Bradnam

Lynley Bradnam has recently been appointed as Professor of Physiotherapy, Graduate School of Health, University of Technology (UTS), Sydney. Previously she was an Associate Professor of Physiotherapy at Flinders University, Adelaide. She is a neuroscientist and her interest in dystonia began while she was studying for her PhD. At that time, her interest lay in understanding the changes in the brain that seem to contribute to dystonia, in particular the role of the cerebellum and whether non-invasive brain stimulation could be used as treatment.

Her work has received two Brain Foundation Australia research gifts and was featured on ABC news in 2013. She has written about dystonia for the Brain Foundation and has published a paper on non-invasive stimulation in a neuroscience journal.

Recently, Lynley has become interested in studying how cervical dystonia affects function, including vision, balance, walking and cognition. She has developed a questionnaire to help identify if movement-related fear is a feature of dystonia for some people. Lynley would like



to see better education for physiotherapists to understand dystonia and offer effective and research-evidenced treatment interventions.

Read Lynley's article in The Brink by Fran Molloy: where she talks about Transcranial Magnetic Stimulation (TMS). <http://www.smh.com.au/national/new-hope-for-dystonia-sufferers-20150720-gibahx>

Sandra Palmer

Sandra Palmer is a Registered Psychologist and yoga teacher, who believes it is vital to work holistically with all clients she sees— working with mind, breath and body. She has a passion for using restorative yoga, breath work, mindfulness and self-compassion techniques, combined with usual psychological talking therapies, to support healing in clients she sees as part of her private practice. These modalities are particularly useful when working with trauma, anxiety, grief and loss, stress and chronic pain.

www.integrativetherapy.co.nz



Facebook

Evelyn Watson in Gore, Southland has created a support group on Facebook. From Evelyn: "we welcome any new members and their families as we share the same interest ... our health! What are you waiting for? Your new friends are waiting for you!"

What is going on here and overseas?

Natural health tips

Need to talk to other sufferers?

The group are working on a fund-raiser

Evelyn Watson's contact details:

Phone: 03 208 5120 or 027 308 6305

Email: watsayyou@xtra.co.nz



New website

One of our new members, Mark Dromgoole, has been developing an improved website for the Network.

To take a peak go to:

<http://thedrop.website/dystoniahome/>

With smart phones becoming more prevalent, we wanted a dynamic responsive website that works better on devices other than standard home computers.

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.

Identity theft

At the NSDA Symposium in Chicago last year, Dr Laura Froeschke talked about the psychological and social distress caused by dystonia and described it as a form of identity theft, or personal invasion. Diagnosis is important because having a name for the condition helps us. She discussed expectations of other people when someone gets sick; they expect you to 'get better soon' and this doesn't happen in dystonia. Both the patient and family can become 'worn out' with this process, hence the need for support networks.

Dystonia Medical Alert bracelets

From our Committee member Jayne Lewington-Lovell:

"Hi everyone – I wanted to share with you how happy I am about the Dystonia bracelet that our group ordered from America last year. It is similar to the medic-alert one except it has Dystonia stamped on and in smaller wording underneath 'check wallet card'. I have found the card and chain helpful in a number of situations. These include an experience at A&E and being unable to talk. Once the emergency staff got the card out of my purse, they knew I had dystonia and what my health number was. Really it saved a lot of time and trouble for all involved, and got me the medical assistance I needed.

More generally I find the bracelet is useful when people want to know why I use a walker/ walking stick or 'what is that thing you have'.. When I first started wearing it I felt a bit like an advertising board, but have got used to it. Now I

figure it's a good way to educate others about our little known condition. If you are

thinking of getting the bracelet I have two recommendations;

- 1) replace the catch with magnets as it's so much easier to get on and off
- 2) make sure to include your NHI number on the wallet card.

Cheers for now - Jayne



Dystonia: muscles behaving badly

Report from Jayne Lewington Lovell on the DNA seminar in Sydney last September

"In September of this year I was fortunate enough to travel to Sydney to attend an awareness seminar hosted by the Dystonia Network of Australia (DNA). Some of you may remember that two members came over for our seminar in Rotorua last year, and it was great to meet up with them again.

Laraine McAnally and Kerrie Jackson booked us into the Wesley Lodge Motel which was just over the road from Westmead Hospital, and as luck would have it some good cafes (which we took full advantage of). These guys were just the hostesses with the mostest for that couple of days. I was a bit apprehensive about travelling over but with a little help from my Aussie friends it was just fine.

The flight was tiring but I was so determined to get to the seminar that I had a plan of action to get me through. These included nana naps, deep breathing exercises and plenty of water. The other thing I did was limit myself to three of the seven speakers as I am mindful of excessive noise, light and crowds of people.

It was a hard choice as I would have loved to hear them all.

So I compromised by adding the Dystonia Q&A session at the end of the day. This was a panel of five of the speakers which worked really well. It was incredibly generous of the group to not only give their own presentations but stay for the day and answer a variety of questions from the audience.

First up was Professor Russell Dale, Paediatric Neurologist; He spoke about cases of kids with Dystonia being misdiagnosed with Cerebral Palsy. Russell also stressed how important it is for health professionals to use the correct terminology to patients and their families; not just for a clear understanding of the diagnosis but to ensure appropriate treatment is followed.

Next was Physiotherapist Melani Boyce who shared some recent research looking

at treatments beyond massage and gentle exercise. These include techniques such as relaxation and mindfulness. She is also waiting for approval for a new study at Westmead Hospital looking at the walking and balance of people with Cervical Dystonia (CD); then investigating whether there are any deviations from the norm and finally if comparisons can be made between CD and other neurological conditions. This could be helpful in (1) learning more about dystonia and (2) sharing treatment ideas for similar conditions.

Keynote speaker, Dr Lynley Bradnam – Professor of Physiotherapy was my third choice. Her field of interest is in the potential for non-invasive brain stimulation as a novel treatment for dystonia. Treatment strategies included; Virtual reality training, Sensorial training through vibration to the neck muscles, and Transcranial Magnetic Stimulation (TMS).

A lot of the data presented went right over my head - if you'll pardon the pun, but I was keen to hear about TMS as Barry Snow spoke of it at our seminar in May. What I did get is that dystonia is a brain network disorder that affects multiple regions of the brain that input into the motor cortex. TMS works when a magnetic coil is held over target areas like the motor cortex to encourage brain plasticity.

Research into whether treatment such as TMS is effective for dystonia patients is still in the early stages. Studies have shown some small significant improvements but more research needs to be done. As Lynley herself said there are many questions remaining around; Types of dystonia? Dose and repetition? TMS on own or combined with other therapies? Patient-administered under supervision?

The thing I found most encouraging from my Sydney trip is that the mindset around Dystonia is changing; and that other fields of treatment apart from Botox are being explored. Westmead Hospital is enormous, and well done them for their continuing research. This was a most productive seminar and I picked up some much needed information and met some great folk.

As well as all that hard work, we also had a lot of fun with the DNA crowd over drinkies and dinners. On the Saturday before flying home Kerrie took me to Parramatta Park where we had brunch by the river. It was a lovely way to end my visit and I'm now looking forward to our seminar next June when we can meet up with our Aussie friends again.



Factoids from the 2016 NSDA Symposium

Latest statistics show focal dystonia affects about 30 people per 100,000 with onset usually between ages 30 and 50; and in generalised dystonia about 3 per 100,000 (so in NZ we could expect 120 people) and onset is early.

Dystonias can be divided into task-specific: writing, speaking; and non task-specific: CD, blepharospasm. In laryngeal dystonia (SD) it is thought about 16% have some family history but this is difficult to establish with dystonia seeing it has only started to be correctly diagnosed during current patients' lifetimes. Most dead people with dystonia would not have known they had it!

In the brain of a dystonic patient both over-activity and under-activity are apparent. In blepharospasm exposure to sunshine could be a factor, and cervical dystonia is related to neck trauma and surgery. In SD viral infections are thought to play a role, and in focal hand dystonia and other task-specific dystonias (e.g. musicians) overuse and too much practice is implicated.

Effects of alcohol: 56% of patients report symptom improvement after 2 drinks. This effect can be replicated with a drug called sodium oxybate (xyrem) – it mimics the effect of alcohol, and has side effects of mild dizziness. In a study of 23 patients, around 55% noticed moderate to significant benefits.

Michael Hammer talked about sensory feedback. If given a styrofoam cup, most people don't squeeze it too hard - but with a glass, more pressure is used to ensure it does not drop. It is speculated this kind of feedback could be faulty in dystonia. This has been investigated by studying the reaction of the vocal cords by using a scope down the nose and generating a puff of air; making it softer, then softer ... to find the softest pressure that the patient can feel. It shows that women have a more sensitive larynx – which might explain the greater incidence of laryngeal dystonia (SD) in women. The experiment looked at SD vs. controls – the SD patients showed greater sensitivity during voicing ('e' and 'ee') and conversational speech. The scientists also compared sensitivity before and after Botox treatment. After Botox the sensitivity was more like the control group.

From the Chair:

A Happy New Year to you all. We hope you enjoy this issue of the Newsletter, and we are looking forward to seeing as many of you as possible at our seminar in Auckland on June 17.

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 \$25 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 for \$5 or more 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,
New Zealand Dystonia Patient Network
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.

Printing and layout by Mike Brabant, Big Red Design, Queenstown.

© NZDPN 2017