

Dr Lynley Bradnam and her team are looking for volunteers for their latest study 'Activity in people living with cervical dystonia'

You are invited to take part in this study if you;

- are between 18 and 65 years old
- have been diagnosed with cervical dystonia
- AND are available for a two-hour visit to our facilities over the next 12 months

For more details phone Lynley on 09 923 4102, or email Lynley.bradnam@auckland.ac.nz

Research will be conducted at the Clinical Exercise Lab in the Department of Exercise Sciences and at the Liggins Institute, Grafton Campus at the University of Auckland.

Approved by the Auckland Health Research Ethics Committee on 28/04/2020 for three years. Reference Number AH1116.

Find a Specialist

Dr Jacqui Allen, (FRACS, ORL HNS) has been added to the NZDPN 'Find a specialist' list. She is a laryngologist who treats spasmodic dysphonia and dystonia of the head and neck region e.g. Meige's syndrome and torticollis. Jacqui works in the private and public health sectors, and accepts referrals from GPs, other specialists and self-referrals.

Contact details are;

- Private practice: Auckland ENT Group, 242 Great South Rd, Greenlane, ph 09 522 2226, info@aucklandent.co.nz
- Public: North Shore Hospital, WDHB

Change to annual subscription

The Committee has reluctantly decided to increase the annual subscription amount by \$5. The new membership fee will be \$35 as from 2021. This is to cover increasing costs for postage as NZ Post no longer supports us with Community Post envelopes; and to continue with our toll-free 0508 number. Although we are also reliant on donations and charitable grants (e.g. Community Grants from Lotteries) we believe our members should help contribute to maintaining our services. Your ongoing support is much appreciated.

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 \$35 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.

New bank account

At our recent Committee meeting, we decided to close our account with the ANZ. They have announced that they are not accepting cheques as from 31 May next year. Unfortunately the demise of cheques is a sign of the times, and we regret the inconvenience for members. The ANZ declined to continue with our 'fees free' arrangement with an online account, so the decision was made to open an Online Business account at Westpac. Westpac offer this service free of charge to non-profits. This new arrangement is working well and the ANZ account is no longer needed. Once it is closed administration procedures for the network and our accountant will be simplified.

Our new account details are:

New Zealand Dystonia Patient Network Inc
Westpac Takapuna
03-0275-0041784-000

Please delete any details for the old ANZ account and replace them with the Westpac details. We will remind you about our new bank account when we send out the invoices for membership in February next year.

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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National and international news and views
Networking Dystonia patients

SAVE THE DATE: Saturday 22nd May 2021



After the disappointment of having to postpone this year's seminar due to Covid-19 restrictions, the Network is pleased to announce that plans are under way for 2021. The seminar will be held in Wellington at the Brentwood Hotel on Saturday 22nd May. As usual the programme will be followed by the Annual General Meeting. More details will be available in next year's newsletters and online at www.dystonia.org.nz.

Brentwood Hotel is located 2.6 km from the Wellington International Airport and 6 km from the city centre. If you wish to stay on-site over the weekend please book directly with them;
Location: 16 Kemp Street, Kilbirnie, Wellington
Phone: 0508 273 689 (0508 BRENTWOOD)
Email: reservations@brentwoodhotel.co.nz
Website: <https://www.brentwoodhotel.co.nz>

From the Chair – Alison Fitzpatrick

Nau mai, haere mai. Warm greetings to you all. What a journey we've had in 2020; lockdowns, online living, huge social change and more. Many of us have had our medical appointments either delayed or cancelled. We've really had to dig deep and use our inner resources in order to stay well. Staying well was one of the themes that came through strongly at our August support meeting held in Auckland. Here's hoping for a relaxing, uneventful festive season and summer for all of us and our loved ones. Stay well and be kind to yourselves.

DYSTONIAN Support Gathering: 10/10/2020

After a couple of false starts and cancellations due to Covid-19, we were finally able to get together for our meeting in August. Once again we met at the Surrey Hotel and it was great to see both familiar and new faces at our half-day session. We kept everything quite organic; we had lots of time to talk to each other and the group about what helps and what doesn't, as we navigate life with dystonia. After the AGM, we had a delicious lunch and then a relaxing Tai Chi session. Once again, it was great to be around dystonians – people who understand.



Photos courtesy of Bruce Norman

Also joining us on the day were several folk from the NZ Essential Tremor Support Group. We are lucky to have connections with the ET group who are close 'cuzzies' to us because our conditions are similar. These similarities were evident with the sharing of our personal stories. The network always enjoys seeing our cuzzies at gatherings and along with Steven and Taki sincerely wish that 'Our liaisons will only strengthen and thrive in the years to come'



Photos courtesy of Bruce Norman

Governance of the NZDPN



From left to right: Jayne Lewington Lovell, Dave Mitchell, Alison Fitzpatrick, Des Sargon and David Barton

The Executive Committee is elected each year at the Annual General Meeting. At the October 2020 meeting the following were voted for;

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Jayne Lewington Lovell, Dave Mitchell

At the Committee meeting in November it was a pleasure to accept two new members. A BIG welcome to Gabrielle Carruthers and Elizabeth McPherson; it is great to have you onboard!



From left to right: Alison Fitzpatrick, Gabrielle Carruthers, Jayne Lewington Lovell, Elizabeth McPherson, Desiree Sargon, Dave Mitchell (David Barton is the cameraman)

Introducing our new Committee members

From Gabrielle:

One day I would like to hear - There is a Cure. I joined the Dystonia Group 3 years ago after being diagnosed with cervical dystonia. At the time of diagnosis I did not know anything about the condition, and was just told I could have Botox injections and there was no cure. I went home and googled and found the Dystonia Group and promptly signed up. Emotionally it was great to attend that year's seminar and meet other people and share information and knowledge. Also to listen to medical professionals who like us are learning and studying our condition -

we learn from them and they learn from us.

I have joined the friendly, hardworking and positive Committee to help where I can and hope to organise some social coffee groups next year.

From Elizabeth:

I am Liz and have been a member of this group for a very long time before just recently joining the Committee. I was diagnosed with Blepharospasm and Oromandibular dystonia which was picked up on an unrelated visit to my GP who then referred me on to a Neurologist for diagnosis and treatment options. I have botulinum toxin 3-6 monthly in the Hospital clinic and this works well reducing my symptoms. The results are evident after about 10 days and reach a peak halfway through the cycle before wearing off until the next treatment is due.

I joined the Committee as I would like to reach out to parents of young children who may have had a diagnosis of dystonia; and to generally highlight the benefits of becoming a member of this national awareness group.

New Initiatives 2020

Coronavirus may have put the country into lockdown this year, but it has also given the Committee the opportunity to come up with some new initiatives for the network. These include;

• Lending Library:

At present we have six items which will be available for viewing on our website. This service will be free to financial members, and include a return courier bag; for non-members we ask for a donation of \$10 to cover costs.

• Children with Dystonia:

In collaboration with the Dystonia Medical Research Foundation USA, The Dystonia Society UK and our 'Aussie cuddies (The Dystonia Network of Australia), we have produced a pamphlet aimed specifically at dystonian families.

Thanks also go to Dr Barry Snow (Movement Disorders Clinic, Auckland City Hospital) and Dr Rakesh Patel (Paediatric Neurologist Starship Hospital); for reviewing the content prior to publication.

• Childhood Dystonia Subgroup:

A group is being formed for those who have children with dystonia. This is for families who wish to be updated and informed about issues relevant to their situation. To express interest and for more information please email info@dystonia.org.nz or phone 0508 DYSTON.

RDNZ Advocacy Webinar

(Report from Des Sargon)

In the last couple of months the Rare Disorder group has had a series of webinars. One of these was from Penny Tucker on effective advocacy strategies. Penny established the 'Advocacy Works' and believes it is easy to get positive outcomes if you do it right.

Advocacy Strategy:

1. Make sure the issue is clearly defined, concise, and you have good reasons for the change.
2. Do due diligence. Who else might be working on this? Clarify that we are all giving the same message. There is strength in numbers so the lines of communication between colleagues must be good. Policy people like to divide and marginalise groups.
3. Map stakeholders. Who are influential and the decision-makers? Start from the top and work down, throughout the whole organisation. Google them. This is all critical to know beforehand.
4. Breakdown the message. State exactly and clearly what you want. Write it down, but only things you would be happy to see on the front page of the Herald.
5. Do a risk analysis. At first 'do no harm'. It is easy to make the situation worse as opposed to better. Be comfortable with the risks.
6. Refine the message. Do not annoy people or be aggressive. Remember it's the issue, not the person.
7. Use personal examples to support the substance of the argument. Use good, up-to-date, relevant statistics to support your argument. Never use unproven facts – admit if you aren't sure about something.
8. See people in person or via phone. Don't use email (as it's likely to be ignored). When seeing politicians find out something good they've done and give them credit for it. Look for a win-win. Give them something out of it as bureaucrats are much harder to deal with.

For more information and to watch the webinar go to: <https://raredisorders.org.nz/about-us/news/webinar-rare-disorder-support-group-advocacy/>

Online Survey Results 2020

In June 2020, an online survey was circulated in New Zealand, Australia and Europe. The aim was to explore the impact of the COVID-19 pandemic on symptoms, activity and quality of life in people living with Dystonia.

Preliminary results indicated that;

- 85% of respondents were treated by a neurologist; of these 64% were usually treated with botulinum toxin injections; of these 25% had their appointment delayed due to COVID-19
- 42 participants reported using self-management strategies such as walking (63%), general exercise (41%), mindfulness (37%), meditation (34%)
- 70% were less physically active than usual
- There was an increase in fatigue and dystonic symptoms
- 30% reported thinking about dystonia more often than usual

These early results show that COVID-19 restrictions negatively impacted on people with dystonia. An example of this was a comment by one respondent who had missed their usual treatment. They knew they were getting worse and were sure that even when they would finally get an appointment it would not be as effective, because the muscles were so tight. The report goes on to say that physical activity and aspects of health-related quality of life were reduced; more so for the non-motor symptoms of pain, fatigue and sleep. On a positive note, self-management techniques assisted in coping with increased symptoms.

Star of wonder – A true Antipodean anthem! Fred Dagg & the Trevs

We three kings of Orient are
One on a tractor, two in a car
One on a scooter
Tooting his hooter
Following yonder star

Oh, oh
Star of wonder
Star of light
Star of beauty, she'll be right
Star of glory, that's the story
Following yonder star ...

