



News+Views

Newsletter 91 – December 2021

SAVE THE DATE: 11th June 2022



Next year's Seminar and AGM will be held in Auckland at The Surrey Hotel on Saturday 11th of June. More details will be available in the first newsletter of 2022, and on the NZDPN website - www.dystonia.org.nz.

Due to the uncertainty of the COVID-19 pandemic, the Network will fully refund seminar registration fees and pre-paid dinner payments should a late cancellation be required.

The Surrey Hotel & Pub is in Grey Lynn, which is close to Auckland city and transport hubs. There is free parking available for guests, with room for disability/ wheelchair vehicles. If you wish to stay on-site over the weekend please book directly with them;

Location: 465 Great North Rd, Grey Lynn
Phone/ Fax: 09 378 9059/ 09 378 1464
Email: reservations@thesurreyhotel.co.nz
Website: <https://www.thesurreyhotel.co.nz>

If the COVID Protection Framework is still in place, all attendees will be required to provide proof of double vaccination, as will be the case with all hospitality venues. This safety protocol is for the protection of our attendees, presenters and hotel staff.

NZDPN 30th Anniversary

Green is the colour that symbolizes thirty years of union. For our group 2022 will be a special milestone, as it will be thirty years since Dystonians in Aotearoa New Zealand began to meet up with others.

Back in 1992, the Holmes Show on TV1 featured a laryngeal dystonia patient from Auckland, David Barton. Coverage of David's voice disorder generated interest up and down New Zealand, and several dystonia patients contacted him. An informal network grew steadily, with patients keeping in touch.

With the rise in numbers, founder members formed the 'New Zealand Dystonia Patient Network'. The newly created NZDPN was then registered as a society with the Charities Commission, and a Constitution was adopted. Our mantra is 'You are not alone' and since David's television appearance, a small group morphed into a network that now has over six hundred on its database. Thank you David!

Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting. The Committee for 2021/2022 is;

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Network Manager: Dave Mitchell

Committee Member: Jayne Lewington Lovell

From Jayne: *"The network is always in need of members to assist in dystonia projects. We are looking for help with putting the newsletter out. Due to increasing loss of hand mobility, this is the last newsletter I am able to produce. To keep the group running and to support other dystonians, please come and join us."* Contacts are 0508 397 866 or info@dystonia.org.nz.

From the Chair ~ Alison Fitzpatrick

Nau mai, haere mai. When I wrote in the last newsletter, there was a real sense of optimism in the air. It seemed as though we had dodged a Covid-19 bullet and that life was going to continue on as before. But then the Delta strain gave us a reality check and our world changed overnight. Now that we are in our 'new normal', one of the challenges we all face is to find ways to stay authentically connected while remaining socially distanced. Social isolation is real; it's a thing. So, take care and see if you can reach out to at least one other person today.

Singing For Better Health

(‘Sunday Morning’ RNZ 24th October 2021)

Arizona State University Musicology Professor Kay Norton studies the healing power of music. She tells Jim Mora that there are studies on both the physiological and behavioural effects of music, and how such effects can benefit those with neurological conditions like Dementia, Stroke or Parkinson's Disease.

“There's nothing that can fix dementia, as we don't know how to cure it. But one of the cool things about singing is that when we sing, we record activities in the brain in a lot of different places; linguistic, feeling, and physical. And because they're recorded in so many places, the fog of dementia, at least until it becomes severe, can sometimes be put aside.

Someone with dementia might not be able to say the name of the song, but in some cases they can sing all of it because it's been memorised so long ago.

Keeping the brain active and agile in this way can keep the memory sharper.

Norton remembers how music helped her own mother, who suffered a stroke that left the right side of her body impaired. She was really distressed. Then I remembered my music training and some of the things I read.

So knowing her mother was a church lady, she began to sing a hymn that would help her move, as the doctors had advised her to do. I stood up and she was facing me and I held her hands ... and I moved my foot and she mimicked me. This happens with people who have temporarily lost their capacity to walk, and also that's used a lot with Parkinson's patients to help them regain their gait.

The marvellous thing about the brain is that it's plastic, it will rebuild, it will find new neural pathways and that's exactly what happened with my mother.

The emotional boost that she got and I've seen other

people get is proof that their brains are not dead, they're still in there.

Even singing alone at home or while driving is a good opportunity to get those feel good chemicals; dopamine, serotonin and oxytocin going and change the subject in your brain.

Singing in a group functions like playing a sport.

Singing alone, literally, take it like a pill.

The deeper you breathe, the more you smile, the more you think about those words, and the more joy you can bring into your life. If you get deep into a song and elevate your heart rate, breathe deeper, and oxygenate your blood, you'll release the feel-good hormones. All that physical activity brings a sense of life back into the body.”

COVID-19 Coping Strategies

It's normal and human to feel anxious right now.

COVID-19 presents a risk to human health and the way we live, and your brain and your body are responding to that risk like they're supposed to! It's what's sometimes called the “fight-or-flight” response; your body knows you might not be safe and it's gearing you up to respond.

Unfortunately, that ‘fight-or-flight’ response doesn't have anywhere to go right now. We are not yet able to fight the virus and we have to respond to it not by fleeing but by staying at home. That means your brain has geared you up for battle, filling your tank with energy and adrenaline, and you've got nowhere to put it. Naturally, not being able to control so many things all at once causes distress. The NZ Mental Health Organisation recommends to;

- keep in touch with your family and friends
- exercise regularly
- do some breathing exercises
- call or text 1737 anytime to speak to a trained counsellor

Another option is to **Laugh More**.

This is because laughter relaxes you through the release of feel-good hormones. The average four-year-old laughs 300 times a day while an average adult laughs only fifteen. So make the time to watch a funny movie or share a belly laugh with your child!

A Smile - Jez Alborough

Smiling is infectious,

You catch it like the flu.

When somebody smiled at me today

I started smiling too.

I passed around the corner

*And someone saw my grin.
When he smiled, I realised
I'd passed it on to him.*

*I thought about my smile and then
I realised its worth.
A single smile like mine could travel
Right around the earth.*

*If you feel a smile begin
Don't leave it undetected.
Let's start an epidemic quick
And get the world infected*

Update from Australia – DNA



Our Aussie cuddies once again marked Dystonia Awareness Month, this September. As reported on their website, they were not going to let lockdown

dampen their spirits.

Three presentations were organised to address various aspects of dystonia. The webinars are now available on the DNA You Tube Channel.

1. Melanie Boyce; Neurological Physiotherapy
<https://www.youtube.com/watch?v=Q0ED7RCgjF4>
2. Dr Tjrk (TJ) Lagrand; Functional dystonia
<https://www.youtube.com/watch?v=t0xZtbDaLuY>
3. Dr Florence Chang; Musicians dystonia
<https://www.youtube.com/watch?v=bIgvkh8oBvI>

Information on Medicinal Cannabis:

The Network is regularly asked for information on the use of medicinal cannabis to alleviate dystonia symptoms. In the articles below are;

- 1: the legal status of medicinal cannabis from the Ministry of Health; and 2: A discussion by Dr Bronwyn Thompson (PhD, MSc (Psych), DipOccTherapy) into cannabis as pain relief.

1: Medicinal Cannabis Agency Factsheet

This information was released 17 November 2021, on the Ministry of Health website. Please check the MoH webpage for further updates.

About medicinal cannabis products;

- You must have a prescription from a doctor before you can access any medicinal cannabis products.
- Your doctor is the best person to advise you whether a medicinal cannabis product is a suitable treatment for you. They will know your medical history, including any other medicines you are taking, and the expertise to assess the risks and benefits.

- Once you have a prescription, the doctor or a pharmacy will dispense the product to you. The prescription will state the kind and amount of product you can obtain.
- Personal imports of medicinal cannabis products are prohibited under law. You cannot purchase products online or from anyone other than a doctor or pharmacist.
- Medsafe have recently issued licenses to several local companies that have met 'Good Manufacturing Practice (GMP)' standards for manufacture of medicinal cannabis products.
- The Medicinal Cannabis Agency expects that the number of verified products will steadily increase over the coming months.

2: How Cannabis Impacts Pain Relief

Thompson, B. (2020). Growing pains: How cannabis impacts pain relief. *Matters of Substance*, 31(1). The research into the correlation between cannabis use and pain relief is currently patchy at best, meaning it's hard to draw strong conclusions about general impacts of cannabis use on pain relief. While it's not clear that cannabis-based products are always effective for managing pain, there is evidence to suggest that it can cause;

- anxiety reduction,
- better sleep (which is important for overall wellness),
- some euphoria and
- a placebo response (based on expectations that cannabis will help).

Relief of any kind for our most troublesome pain problems like neuropathic pain is not very good. Pain is complex, and our understanding of pain is incomplete. For a medical practitioner to prescribe cannabis-based medications, they need to feel that it is safe and effective.

If a doctor isn't convinced then they're not likely to write a prescription. Pharmaceutically produced cannabis products are a known quantity, but the pain relief from these products is not effective for everyone and the financial cost is high. Access to this group of products is therefore limited.

So what can people expect from cannabis when it comes to pain relief? Research shows that, for neuropathic pain, the kind of pain most studied, a combination of both THC and CBD provides the best pain relief effect.

THC can increase anxiety and affect mood temporarily, and is also the only substance in the

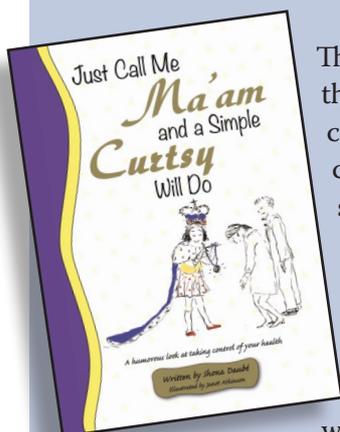
plant known to have a pain-relieving effect. CBD on its own doesn't change pain intensity, although it has an effect on anxiety. Anyone living with persistent pain knows how stressful that is, so the benefit of CBD may be in reducing anxiety rather than pain. CBD may also reduce inflammation, although the data on this is not conclusive.

And finally, in the best studies for neuropathic pain, the reduction in pain intensity is very small, and the effect on what is important for people, like being able to do things in everyday life, is often not measured at all. This means that, while legalising cannabis products will make it more widely available at lower cost, it's possibly not the panacea people want it to be.

Book Review – Shona Daube

(By Jayne Lewington Lovell)

'Just call me Ma'am and a simple curtsy will do: A humorous look at taking control of your health' Daube, Shona: 2021. Pink Cottage Publishing: Carterton, N.Z.



This is Shona's 4th book around the theme of living well with chronic illness. Along with her cat Dorothy, Shona tells us why she feels the need to declare herself Queen of her own health.

Living with a chronic illness can mean having to deal with a variety of health professionals. With this in mind, Queen Shona encourages us to select our healthcare team very carefully. The recommended selection criteria includes;

- * Accepting patients as experts
- * An ability to show empathy
- * Clear communication skills
- * Being able to work in a team

WIN A BOOK:

Queen Shona has some copies of 'Just Call me Ma'am' to give away. To win, email the title of one of her other books and your address to; shonadaube@gmail.com



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.

Internet Banking details are:

NZ Dystonia Network
Westpac, Takapuna
03 0275 0041784 000

Please complete the 'Code', 'Reference' and/or 'Particulars' fields with your name, and whether the deposit is for donation, seminar or membership payment.

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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