

News+Views

Newsletter 93 – September 2022 • Contact us: 0508 397866 or info@dystonia.org.nz • Donations are welcome

Message from the Chair – Alison Fitzpatrick

Kia ora koutou, greetings to you all.

It was lovely to catch up with so many of you at our June seminar. We enjoyed a day of great speakers, new and renewed friendships and the best chocolate cake known to mankind.

Summer is just around the corner, but COVID is not done with us yet. It is important to protect our health by keeping up to date with boosters and wearing masks when we are in crowded places.

Take care and go well.

2022 NZDPN Seminar and AGM



On Saturday June 11th we were at The Surrey Hotel in Auckland for our Annual Seminar and AGM. While the numbers were down on previous years we nevertheless had a very informative day with terrific speakers talking on a wide range of topics. We would like to say a big THANKS to all our speakers, taking time out from their busy schedules to address the attendees. Information from the speakers included:

Julie Rope and Nicola Merrilees – **Rope Neuro Rehabilitation / Duncan Foundation.**

We have always thoroughly enjoyed Julie's presentations and this time Julie was ably assisted by Nicola as well.

The Duncan Foundation is a national support service for people living with neuromuscular conditions, so Julie started off describing what they have been doing on behalf of The Duncan Foundation in support of a small population of those with dystonia, mainly focusing on those with focal hand and cervical dystonia. Over time, the intention is to further explore

treatment options for dystonia, for instance the treatment for focal hand dystonia could be translatable to other dystonias.



Julie

Nicola

Julie described an intensive six-week programme for writer's dystonia, a focal hand dystonia often referred to as "writer's cramp", and outlined the procedure which includes home practice and up to six months of follow-ups after programme completion. We were also shown examples of progress that a patient has made during this treatment showing a definite improvement.

Prior to the commencement of treatment there is a pre-programme assessment. Nicola described what this entails including such topics as education on dystonia and neuroplasticity, assessing readiness, preparing the nervous system and addressing non-motor systems where possible.

That last point is of particular interest as non-motor symptoms have been found to decrease health-related quality of life more so than motor symptoms and Julie and Nicola went on to explain the Motor Symptoms six-week programme which includes neuroplasticity, motor learning, biomechanics, pain theories and psychology.

Motor symptoms (including abnormal muscle contractions, fixed posture and tremor) are like the tip of an iceberg, the non-motor symptoms underneath being many and varied such as pain, fatigue, anxiety and depression to name a few and important symptoms to be considered.

Of course no session with Rope Neuro would be complete without participation in a series of exercises and we were treated to a variety of moves designed to keep various parts of our bodies working as they should do, including the importance of breathing

correctly, so simple and yet so effective. Our thanks to Julie and Nicola for an enlightening and informative presentation; for further information refer to: <https://www.ropeneurorehab.co.nz>

Dieter Dvorak
Clinical Health Psychologist



“Keeping it together”

Dr Dvorak started his presentation by raising questions about keeping it together. He asked WHO is supposed to keep it together; WHAT should be kept together; and HOW do we keep things together?

In the context of chronic illness the WHO are those that are sick, injured or distressed. The response to requests to keep things together depends on two things. 1) who makes them, and 2) whether they are reasonable and appropriate. It does not matter whom or what you are dealing with, it is a human right to express pain and distress; and to adapt our lifestyle and activities accordingly.

Things that might need to be kept together are our behaviour, emotions and thoughts. Dieter wished us good luck with that as that inner voice or impulse cannot be easily controlled. It is difficult to forget about things or to brush them off as the mind is always ticking over.

One way is to train the brain to disengage, so instead of blocking thoughts or reactions it is okay to take them along with you. An exercise like the one below can make it easier to sort out the WHO and WHAT of situations.

Dieter called this the ‘Get out of your mind’ approach;

1. There is a memory/thought/emotion
2. It’s just a memory/thought/emotion
3. Thank you brain but no thanks
4. Imagine putting it in your pocket
5. Repeat as necessary

The presentation ended with a story to illustrate that even in extreme circumstances it is possible to keep things together. The time was somewhere from 1941 to 1944 when France was occupied by Nazi Germany. A German officer demanded food and “things” from a French farmer. The farmer knew that if he refused the officer’s demands that he would be shot. So he decided to live and give the Germans what they wanted. When the Americans came and liberated this part of France the German officer was marched off as a prisoner of war. It was then, at the first opportunity that the French farmer stood up to him and said “NO!”

Like the farmer, life is about being able to accept and work with reality in the service of LIVING and surviving when necessary. It is also about realising that “Accepting” is not “Approval” or giving in, rather it is the

smart choice when faced with a bad situation. The take home message from Dieter was to do what works for you, and use your time and energy to be the best you can. Do not give up ~ there are ways to “be yourself” always.

Rakesh Patel – Tik-Toc Tics and Childhood Dystonia



Our audience enjoyed an entertaining and informative presentation from Dr Rakesh Patel. Dr Patel is a Paediatric Neurologist at Auckland’s Starship Children’s Hospital.

His topic was Tourette’s Syndrome (TS), a neurodevelopmental disorder that begins in childhood

or adolescence. Dr Patel sees many more patients with Tourette’s than those who have childhood onset dystonia.

Tourette’s is characterised by multiple inappropriate tics, which are defined as compulsive movements and impulses that are difficult to control. These can either be motor tics, or vocal – solitary, meaningless sounds and noises, such as grunting, sniffing, snorting, throat-clearing, humming, coughing, barking or screaming. More complex cases involve outbursts of offensive language.

First reported in 1825, TS is underdiagnosed and is four times more frequent in males than females. It is rare in adulthood, meaning the patient can improve with time, experiencing remission or marked reduction in symptoms.

There are strong links between TS and OCD (Obsessive-Compulsive Disorder). The risk of tic disorders increases when certain perinatal events occur: older paternal (father) age, forceps delivery, substance use, and mother’s severe nausea during pregnancy.

Dr Patel also talked about ‘Tik-Tok Tics’. These are psychogenic movements where it seems that children and young adolescents (mainly female) are imitating what they have seen on social media. They became much more prevalent as a result of lockdowns during the pandemic. Unlike other tics, they are not suppressible and have links to mental health issues.

There is no cure for Tourette’s and no single most effective medication. In most cases, medication for tics is not necessary, and behavioural therapies are the first-line treatment.

Dr Patel’s presentation was warmly received, and we left better informed about this challenging neurological movement disorder. Dr Patel is listed in the healthcare referral section at our NZDPN website, and helped to prepare our latest information pamphlet, about childhood-onset dystonia.



Anna Nelson
Surviving, Thriving and Working with a Disability

Anna works at AUT University as the Practice Manager, Disability Support. She experiences Cerebral Palsy, and now in her early 40s, she considers herself a veteran of

“wobble and shake.”

Anna’s session was a masterclass in resilience – hugely enjoyable and fun, and so refreshing. Anna spoke without notes – her anecdotes were authentic and positive. Firstly she spoke about her work in the disability space. Anna has seven staff at AUT who report to her. She tries to employ staff with lived experience of disability where possible. The Disability Support team’s goal is to make the students’ university days as successful as they can be. Ten percent of the student population identify as having a disability. Students fear that if they disclose their disability when applying for a course, it may impact their enrolment (getting accepted into the course) even though this is untrue. This means that the majority of students disclose their disability after their learning programmes begin. Anna has noticed that students with CP and movement disorders are very motivated to learn and achieve.

Next she spoke about her own experience of living life to the full. Anna has had huge loss and grief – her father died at a young age. He was a huge support and believed in her abilities. Anna’s family have always treated her as though she was able-bodied.

Anna’s Techniques for Keeping Positive and Navigating Barriers.

- Reach out to others.
- Remind myself how far I’ve come, and how much I’ve achieved, like learning to drive.
- Socialise as much as possible.
- See the humour in situations.
- Enjoy coffee and wine.
- Be in tune with what works – do I need time out, or time in the sun?
- Remember that others have confidence in me.
- Be mindful of limiting language like “handicapped.”

And finally, Anna’s motto:
Life can be cool if we make it cool.

Next year’s Seminar:

We are looking into our next Seminar being in Christchurch. After contacting our South Island members numbers have been positive so far. Confirmation and details will be in our next Newsletter due in November, and also by email update.

Canadian Research Study: by kind permission of Beverley Smith, Alberta, Canada.

In response to researcher statements that they wish more was known about daily life with dystonia, a patient-initiated survey was undertaken to collect that information.

This project was one year in design stage, one year in survey data collection, and months in data analysis.

The study is at: www.dystoniasurveys.org

The thousands of optional questions about pain, appearance, movement, mobility, symptoms, symptom progression, effects on daily activities, sensory tricks, means to cope, medical consultations, effects and side effects of treatment, moods, outlook, alternative medicine tried, and links to possible cause have been examined.

The website was seen in 83 countries, had 15,984 page views and 5,655 individual views. There were 48 short optional surveys, 1344 questions in total, and over half were checklist. In total over 3,500 questions were asked. The site continues to attract visitors. It has now been seen in 99 countries, and has had 21,491 page views and 8,084 individual views.

Preliminary observations point to several promising avenues of future clinical research.

- a. Patients observed at least six different types of sensory tricks
- b. Patterns of the tricks point to several possible logical explanations, which are outlined
- c. Patterns of presentation, location and progression of symptoms emerged and bear study
- d. For many, dystonia does not disappear during sleep as some had theorised
- e. Links to medication given before dystonia and genetic predisposition emerged and bear study
- f. Patterns of movement delay, gating, effects of music and rhythm were evident and bear study.
- g. Links to other familial movement disorders began to emerge and bear study
- h. The hypothesis that dystonia is caused by stress is not well supported. Results however suggest that treatment for stress may in some patients have triggered dystonia and that dystonia itself can cause stress. Results suggest that at stressful times those with dystonia experience normal muscle tightness, on top of the muscle tightness of dystonia so they may appear to be struggling with stress.

The study and website do not promote any product or service and give no medical advice.

Patients have completed the online surveys despite the challenges dystonia presents to them in looking at a computer, using their hands, sitting comfortably despite pain. They have made the sacrifice of their time and

comfort precisely to help researchers answer the question they were asking.

This study is not a pivotal moment in history to cure dystonia. However patients clearly hope that every researcher of dystonia will look at the results, and will add the results to their knowledge base and then move to that pivotal moment in history.

The Canadian Medical Association Journal has kindly published a patient blog about this project.

<https://cmajblogs.com/dystonia-one-patients-surprising-adventure-to-help-find-answers-to-doctors-questions/>
You are invited also to view the site, and to download the study as you wish.

How listening to music can relieve pain

(‘First Up’ RNZ 5th August 2022)

“According to new research, listening to music you enjoy and especially music that you’ve chosen can help alleviate chronic pain. Music has been used as a pain therapy for decades, says University of London psychology professor Claire Howlin, but she and her colleagues wanted to better understand how it works. “We know that [music can reduce pain] for some people in some circumstances but we wanted to know what was really behind this,” she tells Nathan Rarere.

In Howlin’s study, 286 adults experiencing real-world, acute pain rated their pain levels before and after listening to a music track. The results showed listening to a piece of music you really dislike won’t help your experience of pain at all. The best music for relieving the intensity of their pain is what you personally choose or believe you’ve chosen.

Music that alleviates pain doesn’t have to be of a certain type, Howlin says. High-tempo and low-tempo versions of the same song had an equal effect on participants. Some had great relief from pain when listening to heavy metal, heavy rock and fast-paced dance music.

The experience of music and the experience of pain both have a lot of emotional and personal components and both take up quite a large proportion of our brains. It seems hearing music lessens the sensation of pain because our brains can’t focus on both experiences at once.

When you’re really focused on your favourite music it reduces your brain’s processing capacity for the pain so it’s very difficult for [the experience of both pain and music] to be happening at the same time in your brain. So you’re kind of switching it to focus on this more positive energy. You still might be aware of physical sensation but may be able to feel it’s more positive.

In the future, we may hear music at doctor’s offices and pharmacies, something The College of London is now experimenting with, Howlin says. There is no point in telling people ‘this will be good for your health’ unless people can get access to it. So music is the next frontier for public health.

Governance of the NZDPN

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

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Jayne Lewington Lovell, Dave Mitchell and Ros Bartlett

The network is always in need of members to assist in dystonia projects. 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.

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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