



# News+Views

Newsletter 90 – August 2021

## Message from the Chair – Alison Fitzpatrick

Kia ora koutou; Winter greetings to you all. I am writing this having just returned from an invigorating early morning Tai Chi session at a local park. I am grateful that I can experience this glorious winter's day, with people from all walks of life who come together to find energy and harmony in movement. Movement of any kind is so beneficial for the body and mind, even movement that is disordered. Why not give it a try? Until next time, take care.



Photo courtesy of Bruce Norman

After having to postpone the 2020 seminar because of the COVID pandemic, it was a relief that the meeting could go ahead. About thirty of us gathered at the Brentwood Hotel in Wellington, and we had a day of facts, food and fun. There was also time to reminisce as this year's seminar was dedicated to the memory of Philippa Hooper. Highlights from the seminar provided by your Committee include;

## Dr David Bourke – A Medical Perspective

(Review by David Barton)

Dr Bourke gave an informative and entertaining talk, entitled 'Dystonia 101'. He covered some of the history covering the last 2000 years; from Greek times up to the modern day, with the first use of botulinum toxin to treat dystonia in 1989 and then the discovery of the DYT1 gene which is implicated in generalised childhood dystonia.

The history included the story of the French poet,



Paul Scarron. This image shows one of the first representations of a dystonic trick, or *geste antagoniste*, where the subject is holding a finger to the chin to alleviate the head twisting of cervical dystonia.

*Dr Bourke mentioned that;*

- Genetic testing can be useful in screening for the disorder
- Dystonia can be classified by age of onset (with childhood being generalised most often – or later onset in adulthood being of unknown cause and usually focal)
- Medications or drug use can result in 'tardive' dystonia
- Another type of classification is based on the body part affected.

Dystonia can be thought of as a form of 'hyper-activity' particularly when inhibition of muscle movement is not working as it should. David made the analogy of an 'on/off' switch, where the problem is more with the 'off' control.

Focal dystonia is very 'task-specific' where it may only show up when the affected person is attempting to hold a pen (writer's cramp), or putting in golf (the yips). Dr Bourke shared that he often asks patients to walk along a corridor or up and down stairs, to observe which movements or gait are affected.

The definition of dystonia is: "A sustained, involuntary contraction of muscle that produces an abnormal posture and frequently causes twisting and turning". There are definite and also subtle differences between each patient, and treatments are not helpful for everyone.

At present treatment is for symptoms rather than the underlying cause. The treatment of choice is

injections of botulinum toxin, given in micro-doses. This toxin is derived by purifying the toxin that can cause botulism. When administered to dystonia patients it induces minor weakness which reduces the spasms of dystonia. Botulinum toxin treatment is more successful with some dystonias, such as cervical; than with others, such as Oromandibular Dystonia (OMD) where it can cause weakness in muscles needed for chewing etc.

Next, Dr Bourke gave a brief quiz, showing images of the four main sub-types of cervical dystonia.

He then closed the slide and displayed photos of various people, asking the audience to identify the type of cervical dystonia.



The presentation concluded with a 'Question and Answer' session. Dr Bourke was asked about medical marijuana and CBD oil. He said that there was little evidence that cannabis helped with the spasms of dystonia, but did say in some cases it helped with chronic neurological pain. He made the point that medical marijuana is big business, particularly overseas, and to be careful about only spending what you can afford.

At the conclusion our Network Manager, Dave Mitchell, thanked Dr Bourke for delivering an informative and easy-to-follow talk, and said we appreciated his being so generous with his time and expertise.

### Shona Daube – Coping Strategies

*(Review by Jayne Lewington Lovell)*

In the line-up at the seminar this year was Shona Daube who was speaking about 'Coping well with chronic illness'. Shona is no stranger to dealing with the challenges of health issues, as she has MS (multiple sclerosis).

The first thing she stressed was that we are the experts in how we manage our illnesses. When it comes to living with and making decisions, Shona advised taking control of as many life choices as possible. For her this includes:

- Changing her diet and exercise regime
- Keeping up with research
- Adapting things to suit her needs (like changing her bicycle to a three-wheeler)



- Using her skills to work with others in the MS community
  - Plenty of humour, and the blacker the better.
- Shona has also written a couple of books and brought some along for us to take home. Drawings from them were on her PowerPoint

presentation. Most memorable were her cat Dorothy saying "Get a grip Shona" and the technicoloured tricycle. Thanks to Shona for sharing her unique coping strategies!

### Memories of Philippa Hooper

*(Review by Dave Mitchell)*

David Barton, Jayne Lewington Lovell and Dave Mitchell all spoke fondly of Philippa's long and tireless dedication to the network. Philippa made an impact not only on our organisation but on our members as well. She was involved for almost the whole of the 30 years the Network has been in existence, starting as founding Treasurer and later as Network Manager. Philippa also travelled overseas connecting us with other Dystonia groups to seek out new treatments and to increase our knowledge of this thing called dystonia.

Philippa is sadly missed by all of us; we wish her family well and offer our thanks to have had her serving for so long.

### Diane Clark Manley - Chair Yoga

*(Review by Gabrielle Carruthers)*

Diane has been a yoga teacher for 19 years in the Wellington area. She gave an informative talk and a practical session of chair yoga to the group. Diane also discussed body image, and reiterated that yoga is an exercise that all can do no matter what their age or disability.

Yoga calms fluctuations in the mind and also promotes better breathing. I was indeed surprised at all the varied exercises one could do while sitting in a chair.

On Diane's Facebook page At.Santosha, in the video section you can find three chair videos that when done one after the other become a 1-hour chair yoga class. Also there are two relaxations. One of these is the Rotation of Awareness relaxation, which Diane assured us is particularly good for the mind.

<https://www.facebook.com/At.Santosha>

## Alison Fitzpatrick – Tai Chi for Health

(Review by Jayne Lewington Lovell)

Alison holds a black belt in Tai Chi and after ten years of studying is working towards a 2nd degree black belt. She was just the right person to demonstrate Tai Chi to us as Alison knows the challenges that having dystonia can bring.

It was helpful to have a mix of PowerPoint and practical application, as we learned some facts and then got to practise some movements.

*Three things I learned about Tai Chi are that it is;*

1. based on ancient Chinese medicine and martial arts
2. useful in treating many health conditions
3. a gentle form of exercise for body and mind.

In the second part of the presentation we actually practised some movements. Quite a few of the steps are named after animals which made it easier to remember how to move. This included 'Brushing the Peacock's Tail' and 'White Crane spreads wings'. Alison's take home message was that knowing the science and art of Tai Chi is not necessary; the important thing is that movements should be circular and fluid like the Yin/ Yang symbol.

### Matters arising from the AGM

- Philippa Hooper was remembered for her commitment and service to the NZDPN
- Next year is our thirtieth anniversary which we hope to celebrate at the 2022 seminar
- E-banking is going well and making payment processing a lot more efficient.

### Buffet Dinner

Before sitting down to eat, we raised our glasses and a toast was proposed to Philippa 'our absent friend'. The evening meal was delicious and a great way to end a very busy day. Roll on next year so we can do it all again!



Photo courtesy of Bruce Norman

## NZDPN Joins the Dystonia Coalition



The Network is pleased to report that our group was recently invited to join the Dystonia Coalition. This coalition is a collaboration of medical researchers and patient advocacy groups that is working to advance the pace of clinical and translational research in the dystonias to find better treatments. Since its launch in 2009, forty-nine clinical centres have been established in the United States, Canada, Australia, France, Germany, Italy, and the United Kingdom.

The academic centres all have a special interest in dystonia research, as well as expertise in its diagnosis and treatment of all forms of dystonia.

A conversation with Director, Dr. H. A. Jinnah, MD, PhD took place on 8 June 2021. This webinar was offered to let patients know what the Dystonia Coalition has been doing to bring new treatments to patients. Of particular interest was the 20-minute Q&A session near the end of the presentation.

The link is:

<https://www.youtube.com/watch?v=rI0Vm2boWuo>

Other support groups in the coalition include:

- National Spasmodic Dysphonia Association
- Dystonia Europe
- Cure Dystonia Now
- Dystonia Ireland
- Dystonia Medical Research Foundation
- Dystonia Society
- National Spasmodic Torticollis Association

It is hoped that by globally connecting with other dystonians, the shared goals of quicker diagnosis, better treatments and even a cure, will be realised sooner rather than later.

For more information go to:

<https://www1.rarediseasesnetwork.org/cms/dystonia/>

### Cervical Dystonians Needed for Survey

Dystonia researchers need your help: a questionnaire supported by the Dystonia Coalition seeks to create a list of things that are most troublesome for people with cervical dystonia. If you are diagnosed with cervical dystonia, please consider participating. Specifically, they want you to tell them whether these things are important to you. If they are important to you, they also want to know how important they are.

<https://www.surveymonkey.com/r/2B79WQK>

## Rare disorders NZ – July Update

The Rare Disorders Collective continues to advocate for better healthcare for the 300,000 New Zealanders and their families living with a rare disorder. Latest initiatives include;

### 1. Meeting with the Disability Rights Commissioner

The meeting with Paula Tesoriero (Disability Rights Commissioner) was to let her know where the healthcare system is failing those with chronic and complex medical conditions. Amongst these failings is a lack of awareness, training, research and support. Also discussed was the issue of representation – it is difficult for those with Rare Disorders to be represented if they aren't even invited to the conversations that are happening with regards to their health concerns. Not being represented means not being seen.

### 2. Attending the General Practice Conference and Medical Exhibition.

Chief Executive, Lisa Foster, reported on the annual GPCME in Rotorua she attended on behalf of the rare disorder community. Lisa spoke to a number of key contacts in the health profession about the challenges facing people living with a rare disorder. She also put forward a request to run a workshop next year focusing on education for clinicians.

### 3. Letter to the United Nations

Abandonment is a common term used when talking about equity for people with rare disorders in New Zealand, and what we want is inclusion and to be recognised. This need is important for all people across the world and why there is a current call for a Resolution scheduled at the United Nations in New York this year. If this resolution is successful, then we will have more strength to push our government to gain fairness for people with rare disorders in New Zealand.

## Governance of the NZDPN

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

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Jayne Lewington Lovell, and Dave Mitchell.

Due to ill health and personal commitments, Elizabeth McPherson and Gabrielle Carruthers have had to step down from the Committee. Their hard work has been much appreciated, and they will be missed around the Committee table.

The Network is always in need of members to assist either on the Committee or in dystonia projects.

If you have some spare time please come and join us.

Contacts are 0508 397 866 or [info@dystonia.org.nz](mailto: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 to let us know your name, and whether a deposit is a 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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