



News+Views

Newsletter 83 – November 2018

SAVE THE DATE: Saturday 8 June 2019



Next year's Seminar will be held at the Sudima Hotel in Rotorua on Saturday 8th June. The Network is pleased to offer an accommodation subsidy at the Sudima for financial members. Details are still to be confirmed. The Committee are devising a programme and choosing speakers. As usual the Seminar will be followed by the Annual General Meeting. More will be available in the first newsletter of 2019. Please also check for updates on the NZDPN website at www.dystonia.org.nz.

Dr Lynley Bradnam - Dystonia Research

Dr Lynley Bradnam has recently joined the University of Auckland as an Associate Professor of Neurorehabilitation in the Department of Exercise Science. Lynley has studied dystonia for the last seven years while working at Universities in Australia and is looking forward to continuing her work in New Zealand.

She is a physiotherapist and neuroscientist and her research has included studies investigating function and physical limitations caused by dystonia and the use of non-invasive brain stimulation as a novel treatment for cervical dystonia. The details of future studies can be advertised after approval by an Ethics Committee.

If you wish to express your general interest in participating in dystonia research please email Lynley; Lynley.bradnam@auckland.ac.nz.

Highlights from the 2018 Surrey Seminar

A full day meeting was held at the Surrey Motor Inn in Auckland on Saturday 17 June this year. Our keynote speaker was Dr Barry Snow, and other presentations included; Julie Rope talking about physiotherapy and its application for cervical dystonia patients, Dr Steven Fischer from the Essential Tremor Group (a related neurological disorder with commonalities with dystonia), Alison Fitzpatrick who shared her experience of the 'be.leadership' programme, and a Patient Panel.

The busy day ended with an evening meal which gave us a

chance to relax, unwind and socialise with other dystonians.

Some of your comments

- Thank you all for a well organised conference
- I learnt a lot about other sorts of Dystonia
- It was most interesting to meet Julie Rope and hear about her work with the Duncan Foundation
- Barry Snow explained the medical side of Dystonia so clearly
- It would be good to have the speakers recorded to keep for future reference

Seminar Presentation – Alison Fitzpatrick

~Disability, Accessibility and Possibility~

Be.leadership is a one-of-a-kind programme in New Zealand that is run through the be.accessible movement. The programme is open to anyone young or old, and runs over a one-year period. During that time participants are encouraged to create a more accessible society.

They do this by;

- Looking at different perspectives
- Questioning the status quo
- Experiencing the power of laughter
- Developing individual and collective leadership skills.

In a be.accessible world, personal and societal growth is encouraged for the benefit of all its inhabitants. Alison told us it was a great opportunity for her to rethink not only her own belief-systems, but, those of her community as well. Would she recommend this programme to others – Absolutely!

Check it out at; www.beaccessible.org.nz

Living With Dystonia: What Works For You

The panel discussion led by David Barton, Desiree Sargon and Jayne Lewington Lovell, resulted in a variety of coping strategies in living with dystonia. The group came up with a lot of ideas that were covered in the last newsletter. Below are two items that we didn't have time for on the day.

Coping Tips For Cervical Dystonia

This list was printed in the DMRF (Dystonia Medical Research Foundation) magazine 'Dystonia Dialogue'. It was compiled by members of the Cervical Dystonia Support Forum on Facebook, who were asked to name their top coping strategies.

1. Connect with others who have dystonia
2. Meditation
3. Physical therapy
4. Positive attitude
5. Reduce stress
6. Heat packs
7. Warm baths
8. Laughter



9. Educate yourself and stay informed
10. Caring doctor
11. Botox injections
12. Oral medications
13. Learn your triggers and avoid them
14. Acceptance

Handy tips to maximise your health appointments

Prepare for your visit

- Make a list of questions leading up to your appointment and write them down
- Write down ALL your symptoms
- Get a list of your medications

Don't be afraid to ask questions

- Don't hesitate to voice your concerns
- Don't be afraid of being judged
- It's okay to say 'wait: I want to make sure I understand you correctly'
- There is no such thing as a dumb question.

Take a friend or whanau member

- For another pair of ears when it's hard to keep track of or recall information
- Some news can be overwhelming so it's good to have extra support
- Ideas can be shared on how your support network can be involved in your healthcare
- Medication changes are noted.

Summaries before leaving the appointment

- Repeat the instructions – write them down
- Get the health professional's contact details.

Book a double appointment

- If you have lots of questions the extra time gives you a chance to ask, listen and understand

Be honest

- If you don't understand, speak up!
- If you don't want medication, speak up!
- If the health professional is not listening, speak up!

Seminar Presentation – Julie Rope

Senior Neurological Physiotherapist for the Duncan Foundation; Rope Neuro/Rehabilitation Ltd.

Julie (pictured with Alison Fitzpatrick), is part of the Duncan Foundation which is a national support service for those living with neuromuscular conditions, and those who treat and support them. Their goal is to empower people with these conditions to live to their maximum physical potential.



The Duncan Foundation has established clinics in Auckland, Wellington and Christchurch that aim to provide expert allied health team assessment, rehabilitation plans, education, and support to maintain therapy/ symptom management, (Funded by the Duncan Foundation) and develop clinical networks of experienced therapists across NZ!

They are also developing an Online Hub - This virtual Centre of Excellence will be a place for resources and information for best practice treatment, rehabilitation and MDT support of neurological/neuromuscular conditions. The Hub aims to host the latest evidence-based research, educa-

tion, clinical support and assessment tools that will guide a person with a disorder/disease towards an experienced clinician in the area where they live.

At present the foundation is experimenting with the use of Shakti mats in the management of dystonia. These mats, or as Julie called them - 'Bed of Nails' - stimulate acupressure points on the body.



This stimulation seems to encourage the flow of serotonin most important for regulating digestion, sleep and mood; and release natural opioid painkillers from the spinal cord and brainstem.

These effects were previously noticed in clients with post stroke muscle tone as there was;

- a reduction in tone
- increased ease of movement and
- increased motor activity

While this is all in the pioneer stage, these small advancements are exciting news for all concerned.

This looks hopeful for dystonians, and in the future Julie would like to look more at the overall effect on those with idiopathic Dystonia.

Dystonia is one of the four conditions that the Duncan Foundation is focusing on at present. Julie expressed the wish that the Dystonia community and the Foundation work together to achieve a common goal.

Julie can be found at;

www.ropeneurorehab.co.nz
www.duncanfoundation.org
www.onlineneurorehab.co.nz

Auckland Brain Day – 21st July 2018

(Report by Dave Mitchell)

This year's Brain Day was organised as usual by the University of Auckland and supported by the Neurological Foundation. A range of neurological conditions were on display as reflected in the forty or so groups in attendance.

There were also science demonstrations, panel discussions and activities for the youngsters. People find that it's an excellent way of learning about various brain disorders, often gaining firsthand knowledge from those on the stands.

The photo shows our stand next to cousins from the Essential Tremor Support Group, which works well as we have a close relationship with them.

While attendance numbers were down on previous years, a large number of our pamphlets were taken. We hope that this will work well towards the goal of raising Dystonia Awareness.

Future newsletters will include the date for next year's Auckland Brain Day and of those held in some of the other main cities.

Dystonia: muscles behaving badly - Again!



The DNA Sydney Review by Jayne Lewington Lovell

In September of this year I was fortunate enough to travel to Sydney to attend the Dystonia Network of Australia (DNA) seminar, and,



take part in their inaugural 'Dystonia Awareness Week'. The week comprised of two seminars in Sydney and Adelaide, plus Awareness Days at Westmead and St. Vincent's Hospitals.

When I arrived at the hotel, DNA members had just finished their Awareness event at Westmead Hospital. There was just time to get changed for the pre-seminar dinner. I am the extremely attractive one standing at the back of the



photo!
The next day at the seminar it was lovely to catch up with folk and meet some new ones. Things that caught my interest included; Non-invasive treatment for

tremor, a book recommendation, The NZDPN mantra and the short film 'Dystonia' by Peter Chiverton.

Non-invasive treatment for tremor

Dr. Stephen Tisch is a Consultant Neurologist at St. Vincent's Hospital in Sydney. He is part of a team that have been using MRgFUS (MRI guided focused ultrasound) treatment for Tremor patients.

The procedure takes place in a dome-shaped unit, which is water-filled to assist the accuracy of the MRI directed ultrasound beams. These beams go directly to the thalamus in the brain, where a small lesion is created that blocks the tremor. MRgFUS has been so successful that there are plans to expand the treatment to those with other conditions, such as Dystonia.

Book recommendation

Dr. Bart Post is a Specialist Neurologist visiting from the Netherlands. In his presentation on how Dystonia is diagnosed, he recommended reading 'How doctors think' by Dr. Jerome Groopman.

The NZDPN mantra

My talk about the NZDPN went well and it was a great chance to highlight our group. I stressed the importance of links with the DNA; and our mantra 'you are not alone.'

'Dystonia' by Peter Chiverton

The last item on the programme was the short film 'Dystonia'. The film follows the story of musician Margot Chiverton and her journey in managing dystonia. I especially liked the way the actress accurately depicted the movement and gestures of dystonia. The film can be viewed at; <https://www.youtube.com/watch?v=dCapqLSkb60>

Dystonia Awareness Event

The awareness day at St. Vincent's Hospital went well with a steady stream of people checking out the brochures.

Kerrie showed me around the Botox clinic and we had a quick chat with the neurologists in between patients. It was encouraging to see a good number of people coming up for a look-see and asking the big question – what is dystonia?

I am so glad that I was able to

extend my stay this year; it made a big difference to my energy levels to R&R in the Blue Mountains after the seminar. The weather mostly behaved which meant great views of the Three Sisters rock formations at Katoomba.

My grateful thanks to Kerrie & Laraine for their hospitality; and on behalf of the NZDPN - Well done on a successful Dystonia Awareness Week!

Dystonia is a Family Affair

(By Karen K. Ross, PhD).

When a person is diagnosed with dystonia, the entire family must adjust. Our family felt like the rug was pulled out from under us when my son was first diagnosed with dystonia. Each family member experienced the entire range of emotions. Shock, denial, hopelessness, and helplessness were just the beginning.

Later we felt guilt, responsibility, resentment, and anger. I like to think of a family as a woven tapestry with each person making up a unique colour and thread of the whole piece. When a family member is diagnosed with a chronic disorder such as dystonia, it may feel as if the tapestry is unravelling, never to be woven back together in the same pattern. Some families do come unravelled, but others go on to weave a whole new tapestry, brighter and stronger than before.

The stress of dealing with dystonia on a day-to-day basis can change the way each member reacts and relates to one another. Communication may break down and it may be more difficult to express concerns or share feelings.

Often this is done with good intentions to avoid sharing painful feelings. I once spoke to a dystonia support group where a man brought up his feelings of loneliness and sadness because his adult children never asked him how he was doing or referred to his dystonia. In another instance a woman spoke of her feelings of fear and loss and then said, "My husband wants me to be more positive and not so emotional, but I just can't. I wish he could understand how I feel."

Most people tend to think that it is only the 'patient' whose needs and feelings change, but siblings, parents, spouses, grandparents, and friends are also dramatically affected. They too live with the emotions of grief, fear, sadness, loss, resentment, and anger.

Each member of a family has their own reality and their own set of feelings. Feelings are not right or wrong. While it is important to verbalize feelings, it is just as important to validate someone else's. The woman whose husband wants her to be more positive could say, "I realize that you have feelings that are different from mine, but I still need you to listen to what I am feeling." By stating this to her husband, she is validating what he feels and is helping him to understand that she has a right to her feelings as well.

One of the most meaningful things family members can do for one another is to develop a position of empathy for one another. Empathy is being able to put yourself in another's shoes. It's not the same as pity or even compassion but rather it is the core of understanding. Each and every one of us has the desire and the need to be understood.

The support of family makes it possible for those with dystonia to handle the ups and downs of living with the disorder. I recall one person stated it this way: "It's important for family members to understand that there are good days and bad days—and sometimes good hours and bad



With Kerrie Jackson at Awareness Day, St. Vincent's Hospital

hours—and that patience and understanding and love are the most important contributions they can make.”
Good communication skills and openness can create a nurturing and healing environment for the whole family. Here are a few suggestions:

- It's helpful to start statements with 'I' instead of 'you.' I need, I want, I feel, I like— these are direct statements that communicate what is going on with you.
- If you are the person who has dystonia, let family members know how they can assist you instead of letting them guess.
- Listening is as important as talking. Really listen by making eye contact, and validate what has been said by paraphrasing or saying you understand.
- It is helpful to have family meetings where members can discuss new situations and responsibilities, or talk about any concerns.
- The emotional health of children is affected by their parent's relationship. Parents need to ensure they communicate and work on their relationship.

The persistent intrusion of an illness or disorder affects all aspects of family life. Empathy, good communication skills, an attitude of acceptance, and flexibility will help to foster a resilient family. The challenges of adversity can nurture growth and compassion in each of us if we let it.



Governance of the NZDPN

The Network is run by a Committee that is elected each year at the AGM. The team for 2018/2019 is;

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Dave Mitchell, Roger Terry, Jayne Lewington Lovell

Network Manager: Philippa Hooper

Matters arising from the AGM

- The Network successfully applied for a three-year grant from Lotteries – different amounts for each year, tailored to our budget
- The Network values our continuing relationship with the Essential Tremor and DNA groups.

From the Chair – Alison Fitzpatrick

Greetings everyone! Recently, I've been thinking about the five strategies for wellbeing that we talked about at our last two seminars.

1. Give - your time, your words, your presence
2. Be active – do what you can, enjoy what you do, move your mood
3. Keep learning – embrace new experiences, see opportunities, surprise yourself
4. Connect – talk and listen, be there, feel connected
5. Take notice – remember the simple things that give you joy.

This approach to wellness is something we can have in our resilience toolkits, especially over the next few months. On behalf of the Committee I wish you all the best for the summer festivities ahead.

Online Support Group

Evelyn Watson in Gore, Southland runs the Dystonia New Zealand Support Group on Facebook.

Evelyn's contact details are:

Phone: 03 208 5120 or 027 308 6305

Email: watsayyou@xtra.co.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 \$30 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

ANZ BANK, WAIKANAE

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, NZDPN, 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 for their financial support.

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

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