

# News+Views

Newsletter 80 – November 2017

## Greetings and welcome to the final newsletter of 2017!

This issue will include seminar feedback and reviews from guest speakers Sandra Palmer and Lynley Bradnam. There are also reports from David Barton and Jayne Lewington Lovell who attended conferences in Chicago and Sydney respectively.

## Seminar and AGM 2017

The Surrey cat, as you may remember, oversaw the day's proceedings, making herself available for the mere price of a tummy rub. She found her way onto many laps, gratefully accepted titbits from morning and afternoon tea, and even took part in one of Sandra's mindfulness meditations while stretched out in the sun.



## Save the Date

We are planning our next seminar and AGM for 16 June 2018 in Auckland. More details to follow at our website [www.dystonia.org.nz](http://www.dystonia.org.nz) and in the next newsletter.

## Some of your comments

- Particularly enjoyed presentation from psychologist
- Very helpful information from all of the speakers
- Excellent choice of speakers covering many topics
- Helpful info about coping strategies
- Looking at options for better health
- Gained better understanding of dystonic conditions
- Good to talk to others with Dystonia
- Would love to have a speaker about gene research
- Would like a speaker about childhood Dystonia
- Would like speaker on Feldenkrais Method
- I will share what I learned with my family and friends
- Four people suggested having a microphone all day
- 🐾 There was one request for sardine treats 🐾

## Seminar Presentation – Sandra Palmer

*(Reviewed by Alison Fitzpatrick)*

Sandra Palmer is a registered Psychologist with an interest in the mind/body relationship and the impact of holistic services on those with chronic illnesses. All her treatment methods are evidence-based. She is also someone who "walks the talk" because she lives with an intensely painful and limiting condition caused by a serious injury. Over the

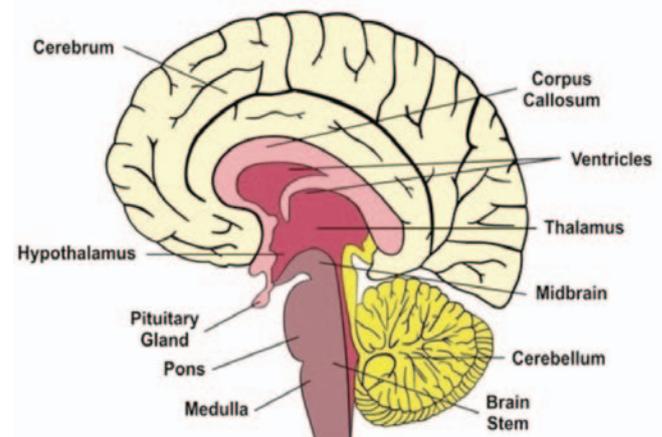
last decade, she has had to pick herself up and somehow learn to carry on. Sandra spoke of the grief associated with any diagnosis of a chronic condition. She gave us some great mindfulness exercises that are useful when dealing with both physical and emotional pain.

## Some tips:

- When walking to the dairy to buy milk notice your surroundings. What colour are the leaves? Are they changing? Falling? Growing? What else do you notice?
  - While having a shower before starting a busy day full of appointments, meetings and tasks, notice the warm water running down your back. Imagine you are standing under a beautiful waterfall.
  - Try to avoid giving your Dystonia a narrative, if you can, even for just a short time. Just be with yourself and with your Dystonia.
  - Last but by no means least, find something you love and do it. You don't have to be perfect at it – just do it.
- Visit Sandra's website at [www.integrativetherapy.co.nz](http://www.integrativetherapy.co.nz)

## Seminar Presentation – Professor Lynley Bradnam

Lynley Bradnam has been part of Dystonia research in Neuroscience and Physiotherapy since 2011. These in-



clude studies from the University of Technology, Sydney; Flinders University; the University of South Australia and Westmead Hospital in Sydney.

Neuroscience is the study of the human brain using non-invasive methods to understand how it functions; in sickness and in health. Central to brain function is the cerebellum which talks to nearly everything else in the brain, and brainstem.

In Dystonia (which is classed as a Brain “Network” Disorder), this process is impaired. Neuroscientists do not fully understand what goes wrong in the dystonia brain, and this provides a basis for ongoing studies.

There has been some small but significant improvement in encouraging brain plasticity with techniques such as Transcranial Magnetic Stimulation (TMS). Early results have shown that repetitive TMS to the cerebellum or motor cortex can be helpful for those with Focal Hand and Cervical Dystonia.

This was evident with handwriting examples which were more legible after treatment; and combined with Botox injections a lowering of pain levels for CD patients.

Physiotherapy: At present there are no specialised services for dystonia patients. Researchers are looking at other neurological conditions to see if comparisons can be made with a view to future treatment programmes.

Study results were consistent in reporting that those with dystonia (especially cervical) had a slower walking speed and a higher fear of falling. This was also the case with the Falls Survey at Westmead Hospital, where dystonia patients had lower levels of confidence in everyday activities. These issues can be further exacerbated by visual problems, as vision-related quality of life is reduced in dystonia.

#### **Vision can be affected by;**

- Light sensitivity
- Headaches
- Burning or stinging of eyes
- The glare of bright lights

In turn this impacts on stepping reaction and walking patterns. It can also help to explain the loss of balance or lack of ability to see obstacles.

Further research is on the way as the physiotherapy team at Westmead Hospital are recruiting now. The results will be used to design new physiotherapy treatments for those with cervical dystonia.

#### **Seminar presentation – David Barton**

David talked about the 3-day NSDA Symposium in Chicago, and shared some updates.



*A group photo taken from behind!*

#### **Factoids from the NSDA symposium**

- Doctors have noticed that patient feedback is unreliable - that's because doctors only see patients when their voice is at or near its worst.
- Researchers believe the problem in dystonia is not so much particular areas of the brain but more the way in which they network with each other.
- Doctors warned against seeking 'cures' on the internet. There are charlatans out there who prey on desperate patients. Avoid the mind-set "It can't hurt to try this" and "I have got nothing to lose". It is fairly easy to spot a website where the emphasis is on soliciting patients and anecdotal testimonials. A charlatan will often say they are the only person offering this 'cure' - there is a reason for that! If you go to the quack and make no progress then the explanation is that it is your fault because you didn't follow the advice carefully or thoroughly enough. If it sounds too good to be true then it probably is!
- There are very few, or no, genetic markers for focal dystonia. The Dystonia Coalition in the United States sponsors research - it is building up both DNA and brain repositories for scientists to study.
- Botulinum toxin injections have been given to patients for SD for about 30 years now. The first injector, Dr Andy Blitzer in New York, has now administered 14,000 Botox shots.
- Traditionally medications are not that effective in treating dystonia, with the exception of DRD (dopa-responsive dystonia). Some patients report that alcohol helps - a similar drug, called sodium oxybate, is being investigated.
- Mindfulness - can be defined as awareness of what is going on around you. A mindful person values what is important to him/her. The aim is to control what you pay attention to. This is not specific to dystonia only of course, but as the saying goes, "I can't always control what happens to me in life, but I can control how I choose to react to it"

#### **Governance of the NZDPN**

The Executive Committee was elected at the AGM in June. Since then Pauline Granich has had to stand down because of work commitments. We totally understand about the need to take care of ourselves and will miss Pauline's positive 'can-do' attitude.

#### **The Committee for 2017/2018 is;**

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Network Manager: Philippa Hooper

Committee Members: Jayne lewington lovell,  
Roger Terry



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NZDPN email: [info@dystonia.org.nz](mailto:info@dystonia.org.nz)

## Book review: 'Not for Sale - Finding Center in the Land of Crazy Horse' by Kevin Hancock

The keynote speaker at the NSDA symposium was Kevin Hancock who is an author and businessman who shared his experiences of living with SD.

Kevin Hancock is President of the Hancock Lumber Company. His company is a sixth-generation family business and has been named as 'The Best Place to Work' in Maine two years in a row.

Kevin developed SD about five years ago. It led him on a journey to an Indian reservation in South Dakota. He wrote a book called 'Not for Sale - Finding Center in the Land of Crazy Horse'. The main theme of 'Not for Sale' is the benefit of losing one of your faculties - in this case, the voice.

### Reflections from Kevin Hancock:

"In the years that followed the partial loss of my voice, I began to see that my old management style was not optimal. It was just old. I began to see that there was a more powerful way to lead and manage, which involved restraint. The secret lay in doing less, not more. Spasmodic dysphonia made me listen. Yes, to others, but, even more importantly, to myself. In a circle of irony, it took losing my speaking voice to find my soul's voice.



Getting lost is the first step to being found. In my experience, this is what happens when a CEO loses consistent access to his or her voice;

- You listen more.
- You talk less.
- You ask more questions.
- You look at more data.
- You show more restraint.
- You let others run meetings.
- You don't break the silence.
- You share responsibility for representing the organization.
- You trust and empower others more completely.

I have jokingly said that all CEOs should lose their voices."

### From the Chair – Alison Fitzpatrick

Kia ora everyone, It is hard to believe that another year is coming to a close. Hopefully summer will decide to make an appearance soon, and the longer days will allow for relaxation and fun times.



### Dystonia: Muscles behaving badly - Again!

Report from Jayne Lewington Lovell on the DNA seminar in Sydney, September 2017

My Sydney trip was very interesting and it was lovely to catch up with folk and make some new acquaintances. The dinner was held on the evening before the seminar, and was a good chance to relax with other Dystonians.

I am the extremely attractive one with glasses at the back, Kerrie is seated on the right-hand side.

This time the seminar was held in an old chapel which made for good vibes, rather than the academic setting of a lecture hall at the hospital.

As with last year I was exhausted from the flight and limited myself to four speakers. First up was Associate Professor Victor Fung, from Westmead Hospital, and member of the International Dystonia Coalition.

His presentation was on 'Emerging concepts in Dystonia'. These included;

- Higher rates of depression
- Muscles work/ fight against each other
- Change of brain function
- The need for mood and physical treatments
- Overflow effect on muscles other than dystonic ones

Victor likened the muscles working/ fighting against each other, to the pushmi-pullyu creature in the film 'Dr Doolittle'. I found this a powerful image to remind me of why I get so tired. Also helpful was his book recommendation 'The brain that changes itself' by Norman Doidge.

Second was a Neurologist from Westmead Hospital, Hugo Morales Briceno. He showcased Cervical Dystonia and spoke about symptoms other than movement and mobility that those with CD can experience. These include lack of co-ordination, gastric reflux and mood disorders. Hugo advised that patients lower their pain and stress levels whenever possible.

Next was keynote speaker Professor George Mellick, a neuroscientist from Griffith University. He reported on a genetic, environmental case study that comprised of 233 Dystonia subjects. The aim of the study was to look for common ground between the participants.

When compared with the control group, dystonians had a higher incidence of;

- Anxiety and depression
- Head injury

- Family history of Dystonia
- Cigarette smoking
- Tremor
- OCD (obsessive-compulsive disorder)

George also talked about the Gene GCH1 that increases the risk of dystonia. He recommended that with an early onset of Dystonia it is helpful to get DNA tested as there is a higher likelihood of genetic mutation.

The last speaker was Dr. Neil Mahant, Neurologist, at Westmead Hospital. His presentation was around dystonia treatments, and the need for a range of options. This is because of motor and non-motor symptoms that are present with dystonia.

As behaviour, mood and motor centres are all on the same circuit; symptoms can include social phobias, CBD and sensory overload. While Botox injections are helpful for the neck, voice, hand and feet; allied health services such as neuro-physio, and occupational therapy could help address multiple issues.

Unfortunately I missed most of the Q&A panel, but am glad to say that the whole day was videoed, and will be made available on the DNA website.

<https://www.dystonia.org.au/>

## Dystonia – Our Tortured Bodies

Dystonia might be a life sentence,  
with its muscle pain,  
continuous spasms inside and out,  
contorted bodies and tremors,  
but it will never destroy  
our minds, our hearts, or our souls

*A poem by Kerrie Jackson (DNA President)*



“...you may have heard that Paddles the Prime Minister’s cat has a Twitter account. Well, so do we...” Our handle is @NZDPN.

Twitter is a great way to read and share information online. Registered users can both read and post tweets and non-registered users can read them but not post anything. This means users have a measure of control over their own privacy, which is often a good thing when looking for information on medical conditions.

Check us out at <https://twitter.com/nzdpn> and help make #Dystonia and #DystoniaAwareness trending topics!

## Obituary – Paddles the First Cat

We are deeply saddened to hear that Paddles died in a car accident recently. His final message on instagram was to; “Live fast, die young. I’ll always be in your hearts. Please be kind to one another. In lieu of fish please make donations to the New Zealand SPCA”

## 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 per annum 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 for \$5 or more 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, WAIKANA  
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,  
New Zealand Dystonia Patient Network  
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, and NZ Post for assisting by providing pre-paid envelopes under the Community Post programme. Printing and layout by Mike Brabant, Big Red Design, Queenstown.

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