



News+Views

Newsletter 79 – August 2017



2017 Seminar and AGM

The Network's Annual Seminar and AGM were held at the Surrey Hotel, Grey Lynn, Auckland on Saturday 17 June 2017. Overseeing the proceedings was the Surrey cat who is an integral part of the hotel workforce. According to management she originally joined the team as a stray but now enjoys supervising day to day operations. Typically found in the guest lounge poised for action (sleeping); she also 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.

The day went well and was a great opportunity to learn more about dystonia-related issues. It was also a lot of fun catching up with old friends and making new ones. Of the forty of us that attended there were three members of the NZ Essential Tremor Support Group. It was a pleasure to meet up with them again and we look forward to continued close links with this group. Another group we also want to keep in contact with is the DNA (Dystonia Network of Australia); as we share common goals and acting together have more chance of realising them. Thanks Kerrie for coming back, and for bringing our new friend Juliette with you.

Highlights of Surrey Seminar

We had a full programme with a variety of speakers from backgrounds in neurology, psychology, physiotherapy and social media. Some of the items presented will be covered here and in the November newsletter. There was however an item we did not have time for and will be covered first. This was the Patient panel discussion - 'Coping - What helps my dystonia?'

In absence of a panel, the information below is gathered from shared meals, over glasses of wine, from off the internet and by trying out what works in coping with the symptoms of dystonia. Where possible the source is referenced, if not then it has been kindly passed on by members who have found something that helps them;

- Free downloadable mindfulness meditations are available on the net. Highly recommended for a start is the four minute body scan – Still Mind.

<http://www.freemindfulness.org/download>

- Tips to save your neck and back working on the computer. Adapted from Tom Seaman. <http://dystonialiving.blogspot.co.nz/>

It is important to think about body posture when using the computer. For some a laptop at a workstation is easier to use, especially with wireless keyboard and mouse. Also important is the type of chair – ideally it needs armrests to support the neck and back.



- A hand-out similar to this one outlining what Dystonia is and its symptoms, to give to your dentist, optician, hairdresser or barber. The Network can supply these. Sometimes it is easier to give someone something to read rather than repeatedly explain why some days it is difficult to speak or stop shaking.

Dystonia is a syndrome consisting of sustained muscle contractions, frequently causing twisting and repetitive

movements or abnormal postures.

Dystonia affects men, women and children of all ages and backgrounds. It is not a psychiatric disorder. The involuntary muscle contractions cause varying degrees of disability and pain, from mild to severe. The resulting involuntary movements and postures may significantly impact daily functioning.

GENERAL CONSIDERATIONS:

- An individual with dystonia cannot control his or her muscle movements.
- An individual with dystonia may need to adopt an unusual posture in the chair, change position often, or stand for select procedures.
- Extra time may be needed to complete a procedure, or procedures may need to be broken up into multiple appointments
- Symptoms of dystonia vary greatly from day to day
- Extra efforts to alleviate anxiety may be appreciated since symptoms worsen with stress
- An individual with dystonia may express sensitivity to light, noise, odours and proximity to electric appliances
- It may be helpful to schedule a client with dystonia with the same hygienist or assistant at each appointment
- Dental professionals are encouraged to be aware of subtle facial grimaces, bite/clenching, tongue-thrust, and other symptoms that may suggest a compromised neuromuscular setting.

Source: *Dystonia Medical Research Foundation*

- Breathing exercises can help to release stress in those times when for whatever reason it is difficult. This particular exercise came from the Physiotherapy Department at North Shore hospital in Auckland. It is often used for hyperventilation; but you don't need to be in panic mode to feel the benefit of relaxing and using your breath to steady yourself.

- 1) hold breath for 6 seconds
- 2) breathe out – gently hold for 3 seconds
- 3) breathe in gently – hold for 3 seconds
- 4) continue 2 and 3 till symptoms pass

Seminar Presentation – Bren Dorman

Bren Dorman specialises in treating spasmodic dysphonia (aka laryngeal dystonia). He is the Clinical Director of the Department of Otolaryngology at Auckland Hospital, and was the first medical professional to offer Botox treatment in New Zealand, starting in 1991.

Dystonia in general affects about 25 per 100,000 of the population and of these only about a sixth has spasmodic dysphonia. SD is defined as a disorder of central motor processing, characterised by abnormal, and often action-induced involuntary movements and uncontrolled spasms in the larynx.

Symptoms present as a trembling voice and signs of strain when speaking, to the point of breaking. Early symptoms may fluctuate but eventually are continuous. There is often a long delay before the correct diagnosis is made, sometimes several years.

One description of SD is of 'trying to talk while being choked' Critchley (1939).

Treatments include voice therapy, surgery and botulinum toxin. These treatments are available at the Auckland Botox Voice Clinic. To date the clinic has administered 641 botox doses to its 70+ patients. Typically, an EMG (Electromyography) unit is used to ensure the injections are put into the correct area of the larynx. Efficiency can be further enhanced by injecting alternate vocal chords and/or by changing the dosage. Decreasing the dose may help with heightened sensitivity, while a longer duration may be achieved by an increase. The benefits of Botox are a marked improvement in the breaks and strains of the patient's voice. A usual pattern after treatment is the elimination of voice breaks and an increase of fluency that can last up to twenty six weeks. One side-effect can be an increase of breathiness, but generally the positive benefits outweigh the negative.

Future developments for SD are extending the duration of the Botox effect, more specific diagnostic techniques and further exploration in genetic research.



Report from Dystonia Australia

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

Kerrie Jackson outlined their association's mission, which over the past year has been to raise public awareness and to become known to as many neurologists as possible. In that time the membership has risen to 100 members, and numbers on the website are just staggering with 6,288 people who have viewed over 35,000 pages. There have been 885 referrals with around 2/3 of them from the medical and allied health websites.

Right from the beginning the decision was made to let the majority of Australian neurologists know about Dystonia and DNA. The DNA banner was flown at an exhibition booth at the Nepean Disability Expo at Penrith Panthers in NSW; and in Perth for the ANZAN (Australian & New Zealand Association of Neurologists) Annual Scientific Meeting.

This exposure was a great opportunity to meet neurologists

from all Australian states and New Zealand, and the DNA team also saw trainees, who are our future neurologists. Brochures and packages were distributed and future contacts made with many industry representatives and other neurological support associations.

New initiatives for the coming year are to go to the Movement Disorder Society of Australia and New Zealand's Annual Scientific Meeting, add more information pamphlets and work with other Dystonia Groups for a Dystonia Awareness Month/Day or Week.

Hopefully an ANZAC awareness event will take place in September next year. DNA will contact the NZDPN after the appropriate government authorities have been approached. This September DNA will be having a Dystonia Seminar in Sydney; information will be available very soon – look for this on our website.



'Once ...' A poem written by a SD patient Copyright © 2017 Victor E. Chears

Once... we laughed
Loud and proud
Maybe we were even known
By our distinctive tone and timbre
Once... we stood
In front of the crowd
Nervously, maybe, but assuredly
As we were about to
Share our remarks
Once... we read aloud
To our children
To our grandchildren
To our congregations
To our friends
Once... we anticipated
Picking up the phone and
Having the exchange
Relishing the wonderful back and forth,
and Embracing the joy of telling the joke or
Making the point
Once... we looked
Everyone in the eye with assurance
As they awaited
The wisdom of our hearts and
The insights of our experiences
To pour from our lips

But now...
Our laughs
Are smiles
Our speeches
Play out in the boundaries of our mind
Our reading
Is confined to moving, soundless lips
Our eyes
Move away
Fearing
The dread
The incomprehension
The emptiness
The frustration
In responding to another
We struggle
Wanting to be
Who we used to be
The one
Who took oral expression for granted
So we sit patiently, silently
As the banter of those around us
Ricochets through the room
Looking for the right time
A quiet moment of safety
To respond

Or not...
We have learned that sometimes our ears
Become our gift and
All we can do is listen and wait
To express
Somehow, some way
Through it all we long...
To sing
To be blend in
To shriek for joy
To not be ignored
To be understood
To feel normal
To believe we are still whole

So we offer and share
What comes from a deeper, more powerful
voice Fortified by observation and wisdom
Because, after all
Our eyes still dance
Our hearts still connect
Our minds still create
We are who we were
We are who we are
Only different and
Just maybe better

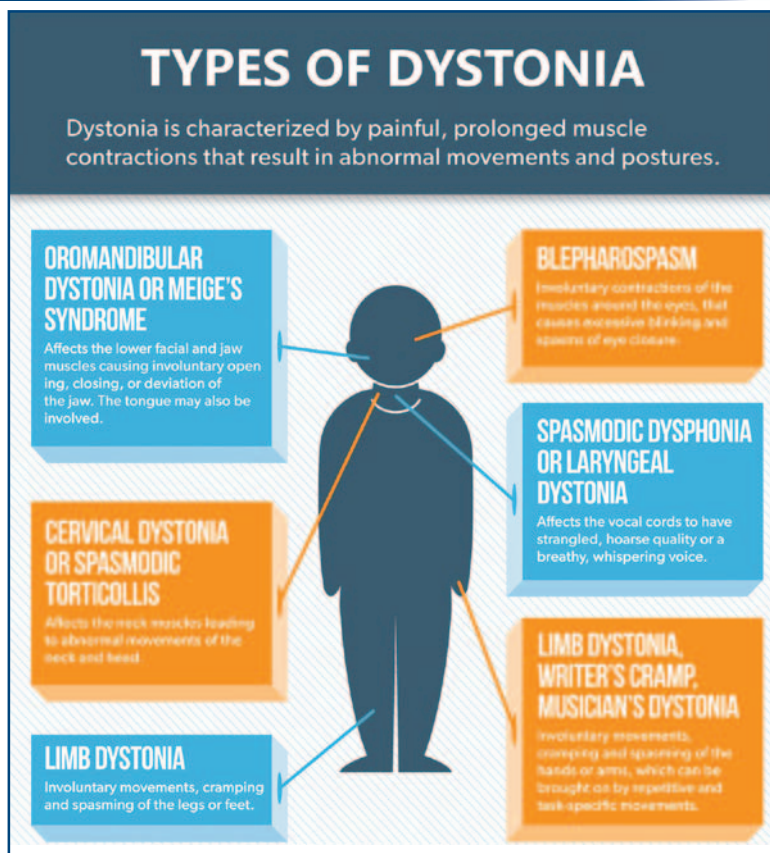
Mark Dromgoole: New website launch

<http://thedrop.website/dystoniahome/> was launched a couple of weeks before the seminar. Mark reported that already queries via the 'we always have time for you - please contact us' form have been received.

Last year Mark approached the Committee about redesigning the network website. With his background in social media he was the ideal person to bring the site up-to-date. There is still the same important information which has been re-packaged to match the digital age. A couple of stand-out features are the striking logos that highlight our mission of support, awareness and research; and under the 'types of dystonia' tab this very clear depiction of what the term dystonia covers. Our heartfelt thanks go to Mark who generously shared his skills to benefit us all. If you haven't checked the site out yet, have a look and see what you think. *Illustration on right*

NZORD - Patients contributing information

NZORD (New Zealand Organisation for Rare Disorders) is requesting that patients send in names of specialists who treat various rare disorders, including dystonia. These will be published in a directory at the nzord.org.nz website. If you are able to contribute information, contact Vikki Ambrose at vikki.ambrose@nzord.org.nz



Readers' comments welcome

We invite comments from our membership on how best we can serve you with any suggestions on how we could improve upon what we currently publish.

Matters arising from the Annual General Meeting

- The idea of an ANZAC Dystonia awareness day was discussed. Folk at the AGM were enthusiastic about the NZDPN and DNA supporting each other in this and other initiatives. Kerrie will contact the committee once she has gathered information on the process of applying / registering with the appropriate Government department.
- Evaluation forms are very important to us. Not only do they help us to give you, the members, what you want, but they are invaluable when applying for funding. Please email or post your evaluation form and any other feedback to us.
- Some members asked about getting newsletters by email. If you would prefer to receive future newsletters electronically, contact: info@dystonia.org.nz

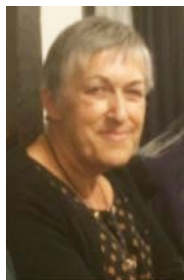
Governance of the NZDPN



*From left to right:
Philippa Hooper,
Roger Terry, Des
Sargon, Alison
Fitzpatrick &
Jayne Lewington-
Lovell*

The Executive Committee is elected each year at the Annual General Meeting. The Committee for 2017/ 2018 are;
Chair: Alison Fitzpatrick
Secretary: Desiree Sargon
Treasurer: David Barton
Committee Members: Pauline Granich, Jayne Lewington Lovell, Roger Terry
Network Manager: Philippa Hooper

NZDPN phone number: (06) 364 7618
NZDPN email: info@dystonia.org.nz



Missing from the line-up this year is Barbara Hampton who has stepped down from the Committee after fourteen years of hard work for the Network. She was the first Support Group leader in Christchurch. Barb has always gone the extra mile in all sorts of situations – meeting with the newly diagnosed and hosting Support Groups in her home. On the

Committee Barb was very constructive and had the knack of getting to the point and moving decisions forward. You and your sense of humour will be sorely missed and oh yes – “Go The Crusaders!”

From the Chair:

Winter greetings to you all. I hope everyone is managing to stay warm and dry. A big thank you to everyone who came along to our June seminar. Once again we had fabulous speakers and a really successful day. Your constructive feedback on the day is greatly appreciated. We will try for an even better day next year!

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 \$25 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, 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,
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 and Allergan 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.

© NZDPN 2017