

DYSTONIA CHRONICLE

Summer Edition

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Auction & Benefit Night

The Auction & Benefit Night on 28 April 2016 at Terranova Bar & Restaurant was a great success. Around 200 people attended, all with the intention of enjoying the atmosphere, the wonderful food and drinks and generously giving to a great cause. DNA cleared \$16,000 from the event. Many Thanks to our hosts and also to those of our members who donated to the night and those who gave auction items.

Laraine McAnally explained her connection to the Scullino Family in her past role of clinical nurse consultant in movement disorder and spoke of Rocco Scullino, in whose honour the Benefit Night was held. Rocco had Parkinson's disease but it was the resulting dystonia that had been so difficult to treat.

As Kerrie Jackson has spasmodic dysphonia, Laraine then spoke in her place about dystonia and DNA and then introduced Jaida and her family. Jaida's grandmother, Ruth, spoke about Jaida's generalised dystonia and treatments but also gave us an insight into her granddaughter's amazing personality and fighting spirit.

Clockwise from top left:

Jaida (guest), Kerrie Jackson, President DNA, Ngawai (Jaida's mother), Guests, Laraine McAnally, Public Officer DNA, Robyn McIlvar, Treasurer DNA, & Phil Mangan, Secretary DNA

See www.dystonia.org.au for all the wonderful snaps taken by Peter Jackson

- Please note the opinions expressed in this publication are not necessarily those of DNA.

Laraine McAnally, Editor





New Zealand Dystonia Patient Network Inc. with Chris Gavenlock Front Row 3rd from left & Kerrie Jackson Front Row 2nd from left

Report on the New Zealand Dystonia Patient Network Inc. Annual Seminar, Saturday 7th May 2016 by Chris Gavenlock

Kerrie Jackson and I attended as guests of NZDPN Inc. The Sudima Hotel in Rotorua was the venue, we were due to arrive in Rotorua on Friday night. Unfortunately there was heavy fog across areas of New Zealand, and after two landing attempts, our pilot decided it was not safe to attempt another landing so back to Auckland it was.

Finding alternate arrangements for all passengers took some time so it was a late night for all concerned. Fortunately Air New Zealand put several of us on the early morning Rotorua flight which saw Kerrie and me at the Sudima Hotel just after 9 am on the day of the Seminar. We were very warmly welcomed by NZDPN Inc. members.

After preliminaries by NZDPN Executive Committee members, the first speaker was **Dr Barry Snow**

Dr Snow established the Auckland Movement Disorders Clinic in 1995. He spoke 'off the cuff', mentioning the history of the 'Dystonia' term from the work of Dr Hermann Oppenheim in 1911 - and Doctor David Marsden's more recent rethink on movement disorders, and the connection in children from a focal dystonia developing into a generalized dystonia. Dr Marsden was instrumental in defining Dystonia as a disease entity rather than as a mental health issue, a conversion disorder.

Dr Snow went into details of genetics, complexities of genes, genes talking to genes, and environmental components. The Human Genome Project has revealed that there are over 20,000 genes so there are many discoveries yet to be made.

Dystonia is a software not a hardware problem where an area of the brain that should be inhibited is overactive, a sensory breakdown. He touched on various forms of Dystonia and how body part, age of onset, type of movement, pulling, twisting, etc. and whether or not there are 'extras' such as tremor, determined the eventual diagnosis of the type of Dystonia a person has. Pain, social embarrassment, disability and consequential psychology of the condition were also discussed.

The various treatments were mentioned. Of particular interest was that the old analogy of the brain operating like a computer has been changed to comparing the brain to a University in that if one faculty such as the

Engineering faculty is taken out, then other related faculties such as Mathematics and/or Architecture would adapt and take over the duties formerly done by the Engineering faculty. An interesting concept when related to DBS and the development of new pathways and how it takes time for these pathways to develop and become useful. Dr Snow was generous of his time in listening to comments and answering questions from the room.

Cervical Dystonia was the next topic addressed by **Julie Rope** neurophysiotherapist.

Julie was a dynamic and passionate speaker and packed a lot into her talk. She said that she will provide access to her notes, Kerrie will follow up on that. Julie referred to Dystonia as a sensorimotor integration of the vestibular, visionary and muscular systems. The importance of balance and centring the body were mentioned along with various techniques.

Like me, Julie is a fan of the Chronicles of a Dystonia Muse.

One quote she mentioned was - 'Minimize fatigue, maximise life'.

We had a lunch break around 12.30 Next to speak was Alison Fitzpatrick on her personal experience with DBS and how much it has improved her quality of life. Alison developed Dystonia in childhood and is very grateful for all the things that DBS has enabled her to do.

David Barton then gave a report on his attendance at NSDA Conference in Chicago.

The last speaker of the day was our own Kerrie Jackson who gave a Power Point presentation of the DNA and all that has been achieved and future plans. Executive of the NZDPN Inc conveyed congratulations to the volunteers who relaunched the Australian dystonia group (now known as DNA) and are keen for an ongoing alliance between the two Networks. It is anticipated that a couple of NZDPN Inc. representatives will attend the proposed DNA Seminar in Sydney on 2nd September.



Kerrie & Laraine at ANZAN, Perth, May 2016

We decided that if we had to let the majority of Australian neurologists know about DNA we had to go to them! So Kerrie & I travelled to Perth and, thanks to Seed Events, we were given a booth in the Exhibition Hall at the ANZAN (Australian & New Zealand Association of Neurologists) Annual Scientific Meeting. We met many neurologists from all states and also trainees—our future neurologists. We distributed brochures and packages and took names and addresses to send packages after the meeting. We also met and net-worked with many industry representatives and other neurological support associations. Well worth the long trip!

Dystonia Awareness Seminar 2 September 2016

Our seminar this year was held at Westmead Hospital in Dystonia Awareness Month and kindly sponsored by Medtronic. Despite quite shocking Sydney weather over 60 people attended; a mix of people with dystonia and their families and health professionals. The presentations were warmly received and evaluation scores showed a mean of 4.7/5. The speakers who generously gave up their time were as follows:

Professor Russell Dale - Forms of Dystonia in Children

Doctor Neil Mahant—Deep Brain Stimulation (DBS), the Neurological Viewpoint

Clinical Associate Professor Stephen Tisch— DBS & Tremor

David Tsui CNC - Showcasing Blepharospasm

Melani Boyce, Physiotherapist — Advances in Physiotherapy in Dystonia

Associate Professor Victor Fung—Understanding the Effects of Botulinum Toxin on Dystonia

Keynote Speaker Professor Lynley Bradnam—Dystonia Mechanisms, Cerebellar Transcranial Magnetic Stimulation & Novel Treatment Strategies for Dystonia

Doctor Kishore Kumar — Investigating the Genetic Basis of Cervical Dystonia

There was also a panel Q&A with Victor Fung, Neil Mahant, Kishore Kumar and Lynley Bradnam which proved very popular.

See website for more information and slides. www.dystonia.org.au

Many of the speakers stayed for the day and spoke with attendees during morning tea and lunch, which was much appreciated. We would like to thank them most sincerely for their wonderful presentations.

We would also like to thank all the attendees, especially those who travelled a distance including: Lee & Ian Pagan from Queensland (Lee runs the Australian Dystonia Support Group), our NZ delegates Jayne Lovell, Phillipa Hooper, Alison Fitzpatrick & Peggy Link (from New Zealand Dystonia Patient Network), Fiona & Jonathon Wills from Canberra, and Caroline Brady & family from Nowra.



Registrants and speakers enjoying lunch



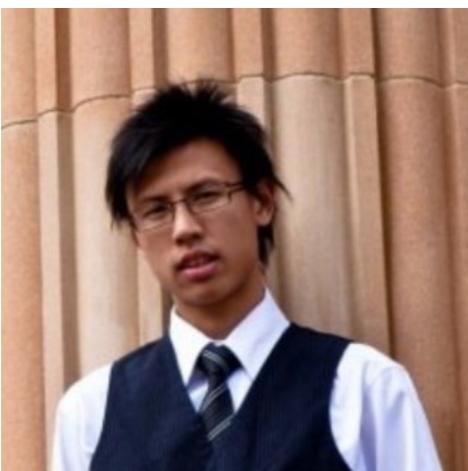
Our panel—L-R Professor Lynley Bradnam / Doctor Kishore Kumar / Doctor Neil Mahant / Associate Professor Victor Fung



Pre-seminar dinner

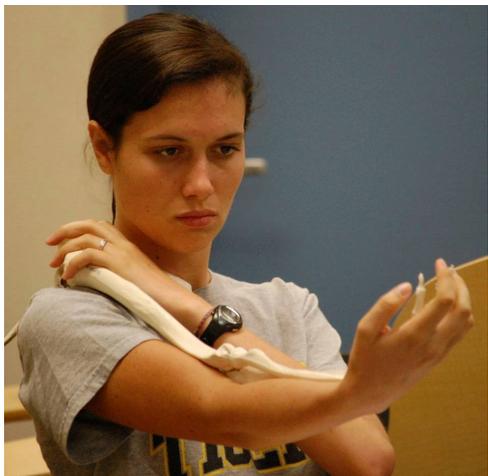


Kerrie & Laraine with the NZ contingent



David Tsui

Jane Shellshear has worked in movement re-education for 20 years. Complementing her qualification as a practitioner of Alexander Technique, Jane's ongoing study in the field of Body Mapping has resulted in becoming the first licensed Andover Educator in Australia. She is a member of the Australian Society for Performing Arts Health and The Australian Society of Teachers of the Alexander Technique.



Redrawing the Maps

At just a few weeks old a baby reaches out and grasps the finger extended to him by mother or father. A few months on and our baby is sitting in a high chair and able to pick up a spoon and drop it to the floor – repeatedly, while his carer retrieves the item each time. The baby seems to find enjoyment in doing this over and over but, as casual observers, we may not realise that he is also busy at the process of myelination of the neural pathway between brain and hand. Fast forward a couple of years and our same child is now engaged in finger painting, learning to play Cat's Cradle, or counting using his fingers. This scenario reflects just the beginnings in the process of maturation of our motor circuitry, our brain in motion. What was a representation of a 'hand' on the surface of the brain of the baby changes over time and with input to establish individual representation of all ten fingers in the child's brain topography. This brain representation or 'map' has changed and now reflects the way our child can use his fingers individually. Maturing of motor skills also requires that gross motor movements be inhibited to allow for fine motor control, so our child can now move an individual finger while simultaneously inhibiting the movement of the rest.

It has been known for some time that cells in the primary motor and sensory areas of the cerebral cortex are associated with different parts of the body. These cells are spatially arranged or 'mapped' in such a way to represent the anatomical correspondence of these parts in the body. The maps are dependent on the motor and sensory experiences of the person, with cortical areas being reorganised to suit the motor planning practices of each particular individual. So feedback from our movements shapes the map.

Since dystonia is a neurological disorder affecting the motor areas of the brain, support and resource sites often list movement re-education techniques like the Alexander Technique or Feldenkrais Method among the options to assist sufferers with their symptoms.

It is important to note that the desired end result of these techniques may well be relief and a change in movement for the person experiencing dystonia - but the *process* used is one of re-education of their brain.

This is effective because, in a very real sense, your body has another existence in your brain. Any one part - your arm, your hand or jaw, is as much a network of sensory nerves as it is a physical form.

As a Body Mapping instructor I work with people to harness the power of their neuroplasticity for healthy movement outcomes. Neuroplasticity describes how the brain is malleable, how it changes as a result of inputs and can 'repair' its function by forming new connections between neurons. It seems that many of us use movement habits that are based on an inaccurate or incomplete perception of the anatomy of our bodies. Our faulty 'map' in the brain is dictating and reinforcing our faulty movement. We come to realise that the way we think our body is designed – whether true or not - dictates how we use our body. We function 'as if' our map were true.

The reason we develop faulty maps is cause for conjecture – it may be that our body maps don't keep up with changes in growth rate or that culturally we place so little emphasis on the sensory information coming to us from our moving sense that the maps become out-dated. We teach children in school that there are five senses. But what of our forgotten sixth sense? Our kinaesthesia or moving sense. Just as little-used pathways in a landscape become indistinct, so too our maps can become vague and misaligned with our anatomical reality without kinaesthesia actively updating the information.

Whatever the explanation, faulty body maps usually lead to excessive tension in our motor functioning and pathologic changes can result. Neuroplasticity means we can change our 'body maps' with grey matter able to grow, shrink, copy, refine, weaken and even sever neural connections. The changes are evident internally as measurable, observable difference in the way movement neurons fire in our brain and outwardly, as a change in our physical movement and abilities. Getting to know not just the truth of our anatomical design but also how to 'embody' that information can redraw our neural maps and deliver us our true movement potential.

The part of the brain known as the cerebellum is responsible for learning new patterns of movement, controlling equilibrium and balance, coordinating signals produced in other parts of the brain and integrating them with information from the spinal cord to plan complex motor actions.

It allows us to carry out movements effortlessly. Equally important is its role in controlling the level of the sensations coming *in* from the body.

The nature of these inputs seems to influence whether changes to the brain occur in an adaptive or maladaptive manner. The sensory information from the environment *and* from our own body is considered to be the 'driver' of our brain's plasticity. The cerebellum has been shown using functional MRI scans to be underactive in dystonia patients and this could be responsible for the excessive response by the brain to feedback sensations from dystonic muscles.

The sustained co-contractions of opposing muscle groups that characterise dystonia cause the twisting or repetitive movements and abnormal postures. Co-contraction results in excessive tension and influences the nature of our sensory experience. In dystonia there is also a decrease in inhibitory mechanisms that can lead to a blurring of sensory motor representation in the brain. Our hand may lose its mature representation on our 'map' as ten individual fingers with individual functioning and comes to be represented in the topography more as a single entity with little ability for fine motor control - as was the starting point for our baby mentioned earlier.

Re-education of the relationship of brain to body, bringing it into full alignment with our true anatomical design, creates a new neural pathway to transmit commands and receive feedback. A new map with a new route to carry out actions and receive sensory information. The change in neural connections can alter the nature of the plasticity driver and the brain moves the body appropriately and easily in response to sensory information.

The discovery of the role of the cerebellum in dystonia paves the way for therapies and behavioural techniques targeting cerebellum functions. Movement therapies start from an empirically observed connection between dystonia and certain patterns of movement. An approach that emphasises overall coordination of the whole body has been shown to be generally more successful than concentrating on training just one part. It seems clear that developing a sense of embodiment, training the kinaesthetic sense, acquiring an accurate and adequate body map and constantly relating the part to the whole is vital in any resolution of symptoms of dystonia. These are the recurrent themes of Body Mapping. .



Inaugural ACT Dystonia Support Group Meeting December 2016

Founding members clockwise from back left: Lornie, Kerrie, Trish, Fiona. Front: Gerda, and Marie. Apologies: Susan Morandini, Margaret and Annette.

On Wednesday 14th December 2016 Kerrie Jackson, President of DNA, together with Fiona, who is a member of DNA and lives in Cook in the ACT, hosted a luncheon for the new Dystonia Support Group in Canberra and surrounding districts. The group has been put together to provide a safe environment for sharing experiences and concerns with other people with dystonia. Many new friendships were formed that day giving comfort, as most people there had never had face to face contact with anyone else with dystonia. You do not have to be a member of DNA to attend as it is open to all people that need support with dystonia, as well as their carers and family. Fiona and Kerrie are organising a weekend luncheon date TBA. If interested please contact Kerrie on (02) 4784 3368 / 0414 648 571 or you can email us at [in-fo@dystonia.org.au](mailto:info@dystonia.org.au).

President's Report

Our mission over the past year has been public awareness and to become known to as many Neurologists as possible. I think DNA has achieved this. DNA now has 96 members and has been growing at a steady rate of 1 new member per week since opening.

We have had another amazing 90 days on our website with 1,008 users who have viewed 7,659 pages with 242 referrals from the medical and allied health websites. We are extremely happy to see our Logo starting to appear on many Movement Disorder Specialist websites across the country. We are slowly making our way through the website adding content that we hope will be of benefit to all.

I have added many practical links on the "other service providers" page. <https://www.dystonia.org.au/living-with-dystonia/links-to-other-service-providers/> .

President's Report (contd)

We have also made available all our DNA Brochures to anyone who would like to download them, You do not need to be a member to do so. Our press release and news stories pages are used for advertising on the DNA website you are very welcome to email us with the details of any Dystonia Event that you would like advertised. If the Event is for a Dystonia Support Group meeting please let us know.

Our banners were flying high for 2 days last September at the Nepean Disability Expo at Penrith Panthers in NSW. There were over 120 booths it was a wonderful way to provide Dystonia Awareness and information to health and community businesses, organisations and of course the public. Thank you to our committee for all your help it was a very successful event! Details of our 2017 events to follow soon.

Until next time,

Kerrie Jackson

President DNA Inc

We hope you enjoy the content of this newsletter. We welcome news stories, items of interest or suggestions for future editions from members.

Please note that the Dystonia Chronicle will be issued more frequently in the future.

We would like to reiterate that the opinions expressed by individuals in this newsletter are not necessarily those held by DNA.

Laraine McAnally, Editor

Organisations and Support Groups

Australia's National Blepharospasm Support Organization

Blepharospasm Australia

Contact Details: John Yeudall
Email: chairman@blepharospasmaustralia.org.au
Website: <http://blepharospasmaustralia.org.au>

Australian Dystonia Support Group ADSG

Contact Details: Lee Pagan Email: ADSG@live.com.au
Website: www.australiandystoniasupportgroup.wordpress.com

NSW

Blue Mountains and Greater Sydney Dystonia Support Group. (BM&GSDSG)

Contact Details: Kerrie Jackson Ph: /
Fax: (02) 4784 3368 or Mob: 0414 648 571
Email: info@dystonia.org.au Web site: www.dystonia.org.au We Meet Bi-Monthly

NSW Blepharospasm Support (BEB)

Contact Details: Stephen Bradley
Mob Ph: 0408 232 338 Email: stevebrad60@gmail.com
website: <http://blepharospasmaustralia.org.au/support/support-in-new-south-wales/>

Newcastle & Hunter District Dystonia Support Group

Contact Details: Elly Bath Mob Ph: 0411 252 110
Email: ellybath@gmail.com

Australian Dysphonia Network (ADN)

Contact Details: Facebook page: Australian Dysphonia Network
Email: australiandysphonianetwork@gmail.com Website: www.australiandysphonianetwork.org

QLD

QLD Blepharospasm Support (BEB)

Contact Details: Grant Rutherford
Email: granrutherford46@gmail.com
Website: <http://blepharospasmaustralia.org.au/support/support-in-queensland/>

NORTH QLD Dystonia Support

Contact Details: Suzanne Bayliss Ph. No: (07) 4032 4033 Email:

s.l.bayliss@bigpond.com.au

Ph: (03) 9929 8536 Fax (03) 9663 7203

Email: efo33132@bigpond.net.au Website:

<http://blepharospasmaustralia.org.au/support/support-in-queensland/>

VIC

VIC Blepharospasm Support Group (BEB)

Contact Details: Elizabeth Foster Ph: (03) 9587 2326

Royal Victorian Eye and Ear Hospital

Web site:

<http://blepharospasmaustralia.org.au/support/support-in-victoria/>

Australian Spasmodic Torticollis Association (ASTA) Victoria

Contact Details: Jan Hoffmann Ph: (03) 9723 6651 Email:

jan@hoffmanns.net.au

web site <http://www.astavic.org/contactus.html>

SA

SA Blepharospasm Support (BEB)

Website:

<http://blepharospasmaustralia.org.au/support/support-in-south-australia/>

South Australian Dystonia Group

Contact Details: Jacqueline Jeremy Email: sadystonia@gmail.com

WA

Blepharospasm Australia (BEB)

Contact Details: John Yeudall Email: [chair-](mailto:chairman@blepharospasmaustralia.org.au)

man@blepharospasmaustralia.org.au

Website:

<http://blepharospasmaustralia.org.au/support/support-in-western-australia/>

BEB Western Australia Support Group Inc.

Contact Details: Lyn Smith Email: secretary@blepharospasmaustralia.org.au

Website: as above. Meet twice a year

NT

NT Blepharospasm Support (BEB)

Contact Details: Carrol Email: gandcalynch@gmail.com

Website:

<http://blepharospasmaustralia.org.au/support-/support-in-northern-territory/>

Dystonia Network of Australia Inc. (DNA)



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Disclaimer

The information contained in this newsletter is of a general nature only.

Please consult a Movement Disorder Specialist or Neurologist if you have any questions about your condition