

The Dystonia Chronicle

Welcome to the first newsletter of our new national association for Dystonia. We hope you enjoy the content and we welcome news stories or suggestions for future editions.

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

Laraine McAnally, Editor

On 14 August 2015 we held a very successful Inaugural DNA Seminar in the auditorium of the Garvan Institute in Sydney. Read about the presenters and their presentations on page 4.

*Please see our list of support groups from all states on Page 10 with up to date contact details. If you would like to advertise in this newsletter please contact DNA by email:
Info@dystonia.org.au or by telephone: Kerrie
Tel: 0247 843368
Fax: 0247 843368*



We "Jumped For Dystonia" at the conclusion of the Dystonia Seminar

In This Issue

Seminar Summary

Advance details of our September 2016 Dystonia Seminar

Details of the main DNA fundraiser in February 2016

Member's Story

Mindfulness

Information on available and future dystonia booklets

Seminar at the Garvan

Professor Marina de Koning Tijssen a renowned European Neurologist was holidaying in Australia in July/August and contacted Margot Chiverton, an advisory board member, to offer to give a presentation on dystonia while here in Australia. We felt this was too good an offer to refuse and a committee comprising Lynley Bradnam, Kerrie Jackson and Laraine McAnally got together other speakers to provide a day of Dystonia. Dianne Petrie, CEO of the Genetic Alliance at the Garvan institute in Sydney offered to host the day in the Garvan auditorium, which took place on 14 August. Including speakers, we had 100 participants comprising people with dystonia, medical, and nursing staff and allied health. The presentations were very well received and a great day was had by all.



Guest Speakers and DNA representatives from top left:

Dr Benjamin Jonker, DNA President Kerrie Jackson and Public Officer Laraine McAnally, Dr Stephen Tisch, Melani Boyce Physiotherapist, Keynote Speaker Professor Marina de Koning-Tijssen (Netherlands), Professor Lynley Bradnam Physiotherapist & Neuroscientist, Dr. F. Chang,, Associate Professor Victor Fung, Helen Brake Manager, Speech Pathology.

Dystonia Seminar Speakers

Dianne Petrie, CEO of the Genetic Alliance based in the Garvan Institute, opened the seminar and welcomed everyone. She gave a brief talk on the Genetic Alliance and then introduced Kerrie Jackson and Laraine McAnally who also extended a warm welcome and spoke about the history and the aims of DNA.

Doctor Ben Jonker gave a very interesting talk, tracing the history of neurosurgery through the ages and then discussing Deep Brain Stimulation (DBS) in a very easily understood fashion.

Doctor Stephen Tisch spoke about Dystonic Tremor and Spasmodic Dysphonia. With regard to dystonic tremor he highlighted that tremor is a common symptom in dystonia and for many years has been overlooked and frequently misdiagnosed as essential tremor. Dr. Tisch discussed the characteristic features of dystonic tremor that allow it to be recognized and its treatment. For dystonic head tremor botulinum toxin injections are often helpful. For dystonic tremor affecting the upper limbs oral medications can be tried and sometimes help significantly. For severe disabling dystonic tremor resistant to medical therapy deep brain stimulation (DBS) surgery is beneficial. Dr. Tisch also spoke about spasmodic dysphonia which is a focal laryngeal dystonia affecting speaking. He described the clinical features of the more common Adductor type which are a fluctuating, strained voice with breaks in pitch and phonation. Conversational speech is most affected and laughing, crying and singing are usually unaffected. Some patients with spasmodic dysphonia experience noisy, effortful breathing (stridor), breathlessness, dis-coordinate breathing) or excessive coughing and occasionally these features are the sole manifestation of laryngeal dystonia. Spasmodic dysphonia is a treatable communication disorder and responds very well to laryngeal botulinum toxin injections, which can significantly restore voice quality and ease of communication. For more information about these conditions patients are encouraged to visit the DNA web site.

Seminar Dystonia Speakers contd.

Professor de Koning Tijssen gave a most interesting keynote address. Her presentation concentrated on an algorithm that has been developed for children and young adults with dystonia to make the journey to diagnosis much easier. She also spoke about “Dystonia Net (Cervical Dystonia arm) “. This is a project of education and networking at many sites across the Netherlands to look at standardising the care of people with cervical dystonia.

Melani Boyce and Professor Lynley Bradnam reviewed papers on the effect of exercise, biofeedback, sensory stimulation and transcranial magnetic stimulation mainly on cervical dystonia, focal hand dystonia and axial (trunk) dystonia. Melani concentrated on the evidence on exercise, citing studies which showed that certain exercise regimes were associated with reduced pain, improvement in coping with activities of daily living and assisting with prolonging the effect of botulinum toxin injections. However, dystonia rating scales were rarely reduced. Melani concluded that results were limited by a variety of reasons such as a lack of controls, small patient studies and similarities between studies, and that more research was required.

Professor Lynley Bradnam examined available research on the effects of electromyography (EMG) biofeedback, neuromodulation and sensory stimulation. EMG biofeedback was also associated with reduced pain and improved quality of life in cervical dystonia and reduction of pain in focal hand dystonia with reduced EMG activity and spasm in blepharospasm and oromandibular dystonia. Sensory stimulation studies showed varied results with some improvement in involuntary muscle activity in cervical dystonia and reduced pain and abnormal movements and more hand control in focal hand/musician’s dystonia. Neuromodulation, trans magnetic stimulation (TMS) studies showed significant improvement in dystonia rating scales and quality of life questionnaires in cervical dystonia but little effect in focal hand dystonia. Professor Bradnam suggested that more studies were required to look at long term benefits of TMS.

Doctor Florence Chang spoke about the Dystonia Coalition, a world-wide group of medical researchers and patient advocacy groups looking at research, treatments and a cure for dystonia. Included in their research discoveries are a new gene mutation for cervical dystonia, the role of the cerebellum on brain plasticity and guidelines for diagnosis of blepharospasm.

Doctor Chang explained the main aims of the coalition, a better understanding of the condition and how it changes, the development of strategies for earlier diagnosis and storage of blood from people with dystonia for use in research. See research study below:

Still open for recruitment

Dystonia coalition project 1

Clinical database and DNA storage

Westmead Hospital, Sydney

Age > 18 with Isolated dystonia

Dystonia onset > 5 years

Collect medical history, videotape examination and DNA

Dystonia onset < 5 years – Natural history study

First visit - Collect medical history, videotape examination and blood for DNA, depression/anxiety questionnaires

Follow up yearly for 5 years

Questionnaires about depression, social phobia and anxiety

Doctor Chang is involved in coalition research. She can be contacted at Westmead Hospital by email florence.chang@health.nsw.gov.au or by phone on 02 9845 7996 for information on current research.

Helen Brake spoke about her role as a speech pathologist in people with dystonia, looking at swallowing in particular. She discussed the stages of a normal swallow and the swallowing problems associated with people with dystonia.

Associate Professor Victor Fung held a very informative question and answer session. Below is a precis of part of the session. Note that he grouped some questions together.

Q. In many countries overseas Trauma Induced Dystonia (after whiplash for instance is medically accepted as a cause. My wife cannot find a movement disorder neurologist to recognise this as they don't accept it or see it as highly controversial and consider her symptoms as psychogenic. Why is Australia so far behind in recognising Trauma induced Dystonia and how can she get ongoing professional support?

Q. Is there any research linking whiplash and dystonia and what if any are your thoughts on it?

Q. Is there a connection between benign essential blepharospasm and laser eye surgery?

A. Professor Fung cited several research studies and conclusions were as follows:

- Dystonia can develop after (significant), (traumatic) brain injury
- Dystonia might occur after peripheral trauma if there is an underlying predisposition
- Psychogenic dystonia is a real disease
- Psychogenic dystonia is curable: most other dystonias are treatable.

Q. What are your thoughts on cutting grains and sugars out of Dystonia sufferers diets. Dr David Perimutter from the USA author of drain brain suggests it would make a huge difference and has had success with patients by changing their diet.

A. There were no research studies available to support or refute these claims.

Q. Do you know of anyone who has tactile triggers? E.g. if someone touches left shoulder/back of the neck area or my left palm I have instant large muscle spasms in my arm, back, neck and shoulder.

A. A recent large study of cervical dystonia patients revealed that around 12.8% had sensory stimulation which could act as triggers for increased muscle activity (reverse sensory tricks). This is a much smaller percentage than those who have a sensory geste to improve their dystonia.

Q. Does your cognitive skills lessen/not as sharp as they were pre Dystonia. I know mine aren't—is it because of the meds, or being worn out all the time eg Memory, concentration span, multi-tasking abilities and sometimes confusion.

A. Dystonia is not associated with reduced cognitive skills. If you feel there is a cognitive issue discuss it with your neurologist.

Q. Much information for patients suggests focal dystonia generally remains in one area but I am in contact with many people with focal dystonia and a large proportion of them have more than one area of the body affected.

Q. It is reported that some people with cervical dystonia will go into remission although the symptoms usually come back. Who is more likely to go into remission? And do the symptoms always come back?

A. In a large study of people with cervical dystonia 32% had progression of their dystonia to other areas mostly upper limbs or face.

In another study 20% of people had a remission from their cervical dystonia, of which more than half had a remission of around 3 years (the others had less remission time). Remissions tended to occur in younger people and early on in the course of their disease.

DNA Trivia Night



Xmas in July theme —
25/07/15. Our thanks to
Springwood Country Club
who kindly donated the room
and their staff to make this a
great first DNA fundraiser.
With 100 revellers and a
charismatic quizmaster we all
had a wonderful evening with
\$3,500 raised which went to
printing and distribution of
dystonia booklets in
September, Dystonia
Awareness Month

Sydney City 2 Surf Fundraiser 2015



Again the sun shone on Sydney for this year's City 2 Surf. \$1220 was raised by Team Dystonia - Claire, Candy, Laraine and Ann - who walked over 14 kilometres in 2 hours 42 minutes, sporting DNA merchandise and beating last years' time by 12 minutes.



Meanwhile Kerrie distributed dystonia leaflets and met up with the team at the end of the walk. Photograph taken by a member of Sydney police with the backdrop of the Pacific Ocean at Bondi.

President's Address

DNA Benefit Night

Please save the date—
7pm Friday 26 February
2015, for our main
fundraiser at the Terra
Nova Restaurant, Horsely
Park, Sydney.

Dinner, raffle and
auction.

Dress—formal.

Price—\$100-120 tba.

Proceeds—to DNA to
assist projects for 2016
including helping
members to attend 2016
September Dystonia
Seminar. Date will be
advertised soon

Welcome to the very first edition of DNA's newsletter. As 2015 draws to a close and I reflect back on what was an amazing first year for our organisation, my heart full, I would like to say a big thank you to my wonderful friend and Co – Founder, Laraine. Without her tireless energy, DNA would still be a dream. A heartfelt thanks to our fantastic committee and the fabulous Advisory Board who have given us great support, guidance and the latest information for all our brochures. You would not believe the many hours of time and thought that goes into just one brochure, let alone 6 with another three on the way. To the gurus of the web – site, one of whom sent me home last December on a daunting mission to learn and become familiar with web sites, the other being our wonderful web designer who has done a remarkable job and continues to do all the complicated entries - we are all extremely grateful to you both.

I would like to take this opportunity to also thank all our members, supporters and families who have helped us through the last couple of years, we are forever in your debt. We have accomplished so much more than we thought we would at such an early stage of our organisation. I look forward to a very busy year in 2016 with the dissemination throughout Australia of our Dystonia Organisation and information and to offer pathways for support to as many sufferers as humanly possible.

On behalf of all of us at DNA, we would like to wish you and your family a Merry Christmas and a very happy and healthy New Year.

Kerrie Jackson
President DNA Inc.

Mindfulness

My experience is what I agree to attend to,"
- William James

So what is mindfulness exactly?

Mindfulness is quite difficult to define because it's known as so many things: a state, a trait, a philosophy, a way of being. It is a quality of mind that can be cultivated; a state of consciousness that promotes well-being; a form of self-regulation that brings attention to the present moment. Maybe you know of it as an ancient practice that originated thousands of years ago. Since John

Kabat-Zinn's research in the 70's, it has become more widely known in the West. Professor Mark Williams of Oxford University describes mindfulness as a "direct knowing of what is going on inside and outside ourselves, moment by moment". It is the process of directing attention to the present experience as it unfolds.

Through the concentrated focus on a particular word, sound, or the breath, we can achieve a relaxed, non-judgmental awareness of thoughts, emotions, and sensations. These simple techniques can focus our awareness and promote a sense of inner peace that can support our well-being and sense of happiness. Mindfulness effectively helps us to gain greater insight; it helps us to become more aware of our thoughts, our feelings, and the world around us.

Aside from being used as a form of relaxation, there are profound benefits of mindfulness. Empirical studies have shown how brain structures can be positively affected by mindfulness. They suggest that mindfulness practices can be helpful in the treatment of health conditions and reduce symptoms. As a side benefit, mindfulness exercises activate the parasympathetic nervous system which supports healing. It calms the sympathetic nervous system, reducing the anxiety associated with a chronic condition. Therefore, developing a mindfulness practice may be considered a helpful tool when living with and managing dystonia.

The goal for my own personal mindfulness practice has been to try and commit to the present moment several times a day in an attempt to habituate the process. This way I have been able to slip into it whenever I have had some space, or time, or when I notice fear arising in my thoughts. This awareness has helped me to see more clearly and pay attention to what is happening in my life and my body. 3 minutes is all that I need to bring me to that space of awareness.

Through this practice, I have found increasing moments of peace where I'm not just a weird diagnosis with a list of symptoms. As my mindfulness disposition and sense of empowerment grows, I am no longer fearful of dystonia. Now more aware and curious, I have the capacity to notice symptoms without judgment instead of being overwhelmed by them.

Through a dedicated practice, mindfulness can be cultivated by anyone. It's not always easy because the brain likes the chatter; however, being present centered, letting go of your thoughts, focusing on the in and out breath, breathing deeply and slowly is a good place to start for anyone. It can be that simple.

Jodie Williams
Mindfulness Coach
MSc in Coaching Psychology
www.nourishthesolution.com (launching January, 2016)

–

BENEFITS

MIND

- enhanced concentration
- improved memory
- attention regulation
- reduces burnout
- increases creativity
- decreases depression
- reduces anxiety

EMOTION

- decentering
- prosocial behavior
- emotion regulation
- empathy
- letting go

BODY

- reduced stress
- decreased muscle tension
- increased pain tolerance
- improved digestion
- improved sleep
- reduces chronic pain

MINDFULNESS

being in the moment

mindful breathing . mindful moving . mindful eating

PRACTICE

Breathe

- choose a space where you have some time to yourself, at home, in nature, in the bath
- let go of the past
- let go of expectation
- close your eyes
- focus on your in and out breath
- if you have your eyes open, focus on something that doesn't move
- breathe deeply and slowly
- start with 3 minutes in this state of focused awareness

ways to be

- EATING
- MOVING
- CLEANING
- DANCING
- LISTENING
- EMAILING
- PLAYING

move

- choose a quiet space
- close your eyes
- stand with feet apart
- loosen your knees
- relax your shoulders
- allow your arms to hang
- notice your breath
- notice the sensations on your body: sun, breeze, warmth
- move slowly
- notice the sounds and smells around you
- focus on each step and movement in your body
- loosen your knees
- relax your shoulders
- allow your arms to hang
- notice your breath
- notice the sensations on your body: sun, breeze, warmth
- move slowly
- notice the sounds and smells around you

Attitudes

- NON-JUDGING
- PATIENCE
- TRUST
- ACCEPTANCE
- LET-GO

eat

- choose a time when you are eating alone
- chew slowly
- focus on the taste, the texture, the sounds, the smell of the mouthful
- eat the whole meal with this focused awareness

scan

- sit or lie comfortably in a place where you won't be distracted
- close your eyes
- move the awareness to each body part: feet, ankles, calves, all the way to the top of your head
- begin by bringing your awareness to your toes

WWW.NOURISHTHESOLUTION.COM

Jodie's Mindfulness References

Brown, K. W. & Ryan R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of personality and social psychology*. 84(4): 822-848.

Davidson, R.J. et al. (2003). Alterations in brain and immune function produced by mindfulness meditation. *Psychosomatic medicine*. 65(4): 564-570

Geer, J.H., Davison, G.C. & Gatchel, R. (1970). Reduction of stress in humans through non-veridical perceived control of aversive stimuli. *Journal of personality and social psychology*. 16, 731-738.

Kabat-Zinn, J. (1990). Full catastrophe living. How to cope with stress, pain and illness using mindfulness meditation. London: Piatkus.

Kirschbaum, C., Wolf, O.T., May, M. (1996) Stress- and treatment-induced elevations of cortisol levels associated with impaired declarative memory in healthy adults. *Life Sciences*. 58(17): 1475-1483

Langer, E.J. & Piper, A. (1987). The prevention of mindlessness. *Journal of personality and social psychology*. 53, 280-287.

Passmore, J. and O. Marianetti (2007). "The role of mindfulness in coaching." *The Coaching Psychologist* 131-137.

Paul's Story

There is one good thing about dystonia, and that is that you don't die from it, although over the past thirty years I could have died from embarrassment hundreds of times over as I struggled to do the most basic things.

My cervical dystonia started innocuously in 1986— I turned my head and while standing in a busy train reading a book and felt a sharp pain, apparently pulling a muscle. I thought it would settle in a few days but the days turned to weeks, leading to a GP and then physiotherapist. Instead of getting better, I progressively got worse. An invisible, undefeatable force was turning my head to the right and pulling it backwards.

Chiropractors, physiotherapist, a Chinese acupuncturist, ice/heat therapy and other remedies that I can't even remember now proved fruitless. Eighteen months after onset, the physio concluded a neurologist might be needed. After a preliminary examination and opinion and obvious scans, the neurologist sent me into the wilderness with a shrug, the confronting word "incurable" and an unconvincing suggestion to try a particular drug which he thought might be worth a go because he had nothing else to offer.

In my subsequent journey of discovery and self-healing I found that one of dystonia's biggest enemies is stress and I now emphasize the need for adequate sleep, exercise and nutrition. Some fun and things to look forward to also help!

It would be typical for those of us with dystonia to think we are the only ones suffering, but those closest to us also suffer as we work out how to live and respond to it. Being angry and depressed doesn't make us good company.

My greatest anxiety was being stared at or looked at. Why? Because I couldn't go anywhere or do anything without my head wildly spasming and swinging around. For a period, eating with a knife and fork was a battle of sheer will and signing a credit card slip at a checkout was a study of stubborn determination.

I can't tell you how much I wanted to take flight and run away from deep embarrassment and humiliation in everyday situations. Knowledge of my own behavior also led somewhat to a fear of it, creating anxiety. Fear and anxiety made my spasms worse and the worse they became the more anxious I was and there was no obvious way to stop the cycle. But life and work somehow had to go on—my wife and two small children depended on me.

A breakthrough clinical trial of Botulinum Toxin began in 1988 and I agreed to participate in the experiment, at the same time devouring books like *The Power of Positive Thinking* by Norman Vincent Peale, *Your Healing is Within You* by Anglican Canon Jim Glennon, and *The Power of your Subconscious Mind* by a Dr Joseph Murphy. For me, resolution and emotional relief came about most effectively when I consulted a psychologist who was also a skilled, compassionate, patient and understanding hypnotherapist.

I became familiar with rational-emotive therapy which made me aware of the voice inside our heads that can encourage or defeat us, and began to regularly practice periods of progressive relaxation. I now go through life pretending that I don't have dystonia. Yes, it's always there but it's no longer my focus. I try to maintain a confident, can-do attitude even though dystonia is a bugger of a thing to live with!

Organisations and Support Groups

Australia's National Blepharospasm Support Organization

Blepharospasm Australia

Contact Details: John Yeudall

Email: john_yeudall@yahoo.com Website: www.bebaustalia.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

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: grantrutherford46@gmail.com

Website: www.bebaustalia.org.au/support-groups

NORTH QLD Dystonia Support

Contact Details: Suzanne Bayliss Ph. No: (07) 4032 4033 Email: s.l.bayliss@bigpond.com.au

VIC

VIC Blepharospasm Support Group (BEB)

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

Royal Victorian Eye and Ear Hospital Ph: (03) 9929 8536 Fax (03) 9663 7203

Email: efo33132@bigpond.net.au Website: www.bebaustalia.org.au/support-groups

Meet: 3 times a year at the Royal Victorian Eye & Ear Hospital

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: www.bebaustalia.org.au/support-groups

South Australian Dystonia Group

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

WA

Blepharospasm Australia (BEB)

Contact Details: John Yeudall Email: john_yeudall@yahoo.com

Website: www.bebaustalia.org.au

BEB Western Australia Support Group Inc.

Contact Details: Lyn Smith Email: bebwa@bebaustalia.org.au

Website: www.bebaustalia.org.au Meet twice a year

NT

NT Blepharospasm Support (BEB)

Contact Details: Carrol Email: gandcalynch@gmail.com

Website: www.bebaustalia.org.au/support-groups

Dystonia Network of Australia Inc. (DNA)



Registered Charity ABN: 66 348 949 649

9 Denman Parade LeuraNSW 2780

Tel/Fax: (02) 4784 3368

Email: info@dystonia.org.au

Web site: www.dystonia.org.au

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