

News+Views

Newsletter 92 – April 2022 • Contact us: 0508 397866 or info@dystonia.org.nz • Donations are welcome

NZDPN Seminar: Saturday 11th June 2022



This year's Seminar is being held in Auckland at the Surrey Hotel, it's our 30th Anniversary! All members are invited to attend for a fun day of learning, networking and companionship, with partners, family and friends. The Seminar will be followed by the Annual General Meeting. The Surrey Hotel & Pub is in Grey Lynn, which is close to Auckland city and transport hubs. There is free parking available for guests, with room for disability/ wheelchair vehicles. If you wish to stay on-site over the weekend please book directly with them;

Phone/ Fax: 09 378 9059/ 09 378 1464
Email: reservations@thesurreyhotel.co.nz
Website: <https://www.thesurreyhotel.co.nz>
Location: 465 Great North Rd, Grey Lynn

Members attending the seminar must be double vaccinated against COVID-19 and present the vaccine pass. This is required by The Surrey Hotel. We advise attendees to be prepared for their vaccine passes to be checked and to have ID at hand if required.

This year the Network is again offering an accommodation supplement for members who travel a significant distance to the Seminar. The subsidy is \$125.00 per room, for one night's stay in Auckland. It is available to 2022 financial members (current as at 31 March 2022); and who live in the South Island, or north of Wellsford or south of Pukekohe in the North Island (as defined by the Auckland 'Super'

City boundary).

Just book and pay for your room as usual, then for reimbursement submit your hotel receipt for either the 10th or 11th of June 2022 to the Network. Please send to info@dystonia.org.nz or PO Box 34 259, Birkenhead, Auckland 0746.

N.B. Due to the uncertainty of the COVID-19 pandemic, the Network will fully refund seminar registration fees and prepaid dinner payments should a late cancellation be required.

Registration Fee for attending the Seminar

Members: \$45.00 single or \$80.00 per couple

Guests: \$85.00 single or \$140.00 per couple

Meals/ Food provided with Registration Fee

Morning Tea, Lunch, and Afternoon Tea

Other Meals

Breakfast(s) and the Saturday evening meal (optional) are to be paid by attendees. When registering for the seminar please indicate whether you wish to join us for dinner. It will help us with planning if you pre-pay the cost of the evening meal of \$50.00 per person with your registration fee. A registration form is included with this issue of the newsletter or can also be downloaded from www.dystonia.org.nz

Seminar Programme – 11th June 2022

- 9.00 Registration - Tea/Coffee on arrival
- 9.30 Welcome and introduction of NZDPN Committee, Chair Alison Fitzpatrick
- 9.45 Dr Rakesh Patel – Childhood dystonia and Tik Tok Tics
- 10.45 Update from the Dystonia Network of Australia (DNA)
- 11.00 Short Break
- 11.15 Julie Rope – Neuro rehabilitation
- 12.30 Lunch
- 1.30 Dieter Dvorak – Keeping it Together
- 2.15 Anna Nelson – Surviving/Thriving: working with a disability.
- 3.00 Evaluation of the day
- 3.05 Short break
- 3.20 NZDPN Annual General Meeting

Speakers are happy to take questions after their presentations, but please restrict these to general issues rather than your own diagnosis and treatment.

NZDPN Annual General Meeting

AGENDA

- Apologies
- Minutes of Previous AGM
- Financial Report
- Annual Report from Executive Committee
- Election of Officers
- General Business

All members are welcome to attend the AGM, but you need to be a 2022 financial member in order to vote.

Evening Programme

6.30 Buffet dinner at the Surrey Hotel is optional, but we hope you will stay for the meal as this is an excellent way to socialise with other dystonians.

Speakers



Dr Rakesh Patel

MBChB, Dip Paeds, FRACP
Dr Rakesh Patel is the Chairman of the NZ Paediatric Clinical Network and Consultant Paediatric Neurologist at the Starship Children's Hospital in Auckland.

Dr Patel's main interests are general paediatric neurology and neuromuscular disease. He is an AOCNA national delegate, clinical advisor to MDA NZ, an honorary lecturer in Paediatrics at the University of Auckland and a member of the Royal Australian College of Physicians Advanced Training Committee.



Dieter Dvorak

Clinical Health Psychologist
Dieter initially worked in accident rehabilitation as a case manager and rehab advisor 1981 to 1993 (Germany)
He studied psychology at the Eberhard Karls University Tuebingen (Germany) 1994/95 and Massey University to become a Clinical Psychologist (1996 – 2001)

Dieter worked initially in Adult Mental Health 2001 to 2005 but since then in physical health (Regional Acquired Brain Injury service 2005 to 2011 and

Waitemata DHB Pain service since 2011)

He created the Flexible Pain Response workshop as an educational intervention designed to help chronic pain patients learning how to minimise the impact of medical treatment resistant pain on their quality of life.

He is one of Auckland's most experienced "Acceptance and Commitment Therapy/ACT" practitioners. "ACT" is the newest form of Cognitive Behaviour Therapy/CBT on which the chronic pain course is built upon.

Julie Rope and Nicola Merrilees

- Rope Neuro Rehabilitation / Duncan Foundation



Julie Rope

Julie Rope is an Auckland based physiotherapist who has a passion for working with the neurological patient population, ensuring they have access to assessment and support wherever they live in New Zealand, and sharing knowledge with other professionals about neurological condition management. Julie leads the expert team of Duncan Foundation-accredited, neuromuscular condition-specific clinicians, across New Zealand.

Nicola Merrilees is an Occupational Therapist, specialising in neurology and specifically, rehabilitation of upper limb impairments. Nicola has been delivering services on behalf of the Duncan Foundation to people with focal hand dystonia.



Nicola Merrilees



Anna Nelson

Anna works at AUT University as the Practice Manager, Disability Support. She has worked at AUT for over 12 years, and in the disability tertiary sector for over 15 years.

Anna experiences a physical disability, Cerebral Palsy, and now in her early 40's, Anna considers herself a veteran of 'wobble and shake'. She rarely sees her disability as a limitation and lives life to its fullest.

The Botox Clinic during COVID

As a veteran of over 80 Botox injections for my laryngeal dystonia since 1991, I was not sure what to expect when I was given an appointment at Neurophysiology at Auckland City Hospital in February. It was Level Red. The world had changed since New Zealand had, more or less successfully, kept COVID out of the community for many months.

After passing through reception where I was courteously asked several screening questions, it was up in the lift to Level 8. The waiting room was empty; no nervous but excited patients swapping war stories about their struggles with SD and how they had been coping since the previous injection. No opportunity to leave any Network pamphlets in the room and invite new people to join. Double-masked as a precaution, I was ushered into a drab corridor with single chairs spaced 3 m apart. Masked up, and too far apart, conversation was not possible.



Eventually I was called in to the treatment room. Drs Vokes and Walker were in full PPE, with plastic gowns and N-95 masks. But otherwise it felt like a normal appointment - friendly banter, confirmation

of the dose for this treatment, and then the usual hooking-up to the ECG machine before the needle enters the larynx.

With our hospital system under extreme stress, I can only admire, with gratitude, the professionalism and commitment of our healthcare professionals.

Message from the Chair ~Alison Fitzpatrick

Kia ora koutou, greetings to you all.

The last couple of months have seen the Committee working on preparations for our June 2022 seminar. We are super excited about this one, because it is the network's 30th anniversary.

As always, we have a wonderful array of speakers and guests lined up, so we can guarantee a day of interesting conversation and information. It's a celebration too, so there will be cake!

As we know from the last two years, everything is COVID dependent – but we have decided to plan for a successful day and hope for the best.

Can't wait to see you there!

Breathing well - Dr Tania Clifton-Smith

Breathe Nose, Low and Slow.

(‘Nine To Noon’ RNZ 14 October 2021)

Dr Clifton-Smith speaks with Kathryn Ryan about her new book ‘How to Take a Breath.’ “Your breathing is the conductor of the orchestra. If you’re not breathing well nothing will work in harmony,” says physiotherapist Tania Clifton-Smith. The breathing dysfunction specialist has 30 years’ experience and is co-founder, along with Dinah Bradley, of the first independent Breathing Pattern Disorders clinic in Australasia. They developed the BradCliff breathing method to reduce stress, improve sleep, think clearly and improve performance in sports and at work.

“The first step in good practice of breathing is to check during the day on your body and understand how it’s feeling when you’re stressed, she says.” [Have] little reminders to stop, feel your body, how tense are you, are your shoulders tight and tense, then feel your breath. Once you’ve calmed, tune up with yourself, ‘am I working on the most important thing that I should be working at?’ or ‘what am I feeling? What’s going on?’

So, its stop, self-awareness, then follows the breath.

Even if you’re not doing it well, once you start to observe the breath, we know in science it actually takes you towards the relaxation chemicals in the body.

The next step is to check how you are breathing, which you can do by putting one hand on your upper chest and one on your abdomen. The BradCliff motto is to breathe through the nose, low (your abdomen moves first and most), and slow (exhaling slightly longer than inhaling). When someone comes in and says I can’t breathe, it’s so important to unpack what you mean. Is it because you are unfit or are you so much in your mind that your nervous system has revved your breathing rate up?

When we’re breathing well, the autonomic nervous system is in a ‘green’ state, which is rest, digest and calm. In comparison, over breathing can trigger more adrenaline and switch on stress hormones, putting the nervous system in a ‘red’ state.

If someone finds that they’re starting to really rev up and get into anxiety, we’ve got something called

'BradCliff five by five' where you breathe into cuffed hands for five breaths, rest for five breaths, back into your hands for five breaths, and keep doing that until your brain starts to clear. And what that does is it just retains some of the CO2 back into the body that starts to stabilise that red and green I was talking about, so it tends to take the body back into the green. Breathing well through the diaphragm actually cleans the immune system, says Dr Clifton-Smith. Literally the mechanics of breathing well cleans the brain, makes you have a robust lymphatic system, good for movement, very good for voice and gut health."

Rare Diseases NZ

RDNZ recently had a very interesting discussion with Catherine Ryan on Radio NZ about the problems associated in achieving a correct diagnosis for neurological conditions. Details below:

<https://www.rnz.co.nz/national/programmes/nineteennoon/audio/2018832751/ten-years-for-a-diagnosis-overlooked-and-let-down-rare-disorders-group>

https://www.rnz.co.nz/audio/player?audio_id=2018832751

RDNZ are very active in advocacy for neurological groups, their website, <http://www.raredisorders.org.nz/> contains a lot of information regarding current and future proposals.

Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting. The Committee for 2022 is
Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Jayne Lewington Lovell and Dave Mitchell.

A big THANKS to Jayne for producing our newsletters for the last five years. The Committee and our membership really appreciate the contribution you have made! The network is always in need of members to assist in dystonia projects. To keep the group running and to support other dystonians, please come and join us. Contacts are 0508 397 866 or info@dystonia.org.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 \$35 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

Westpac, Takapuna

03 0275 0041784 000

Please complete the 'Code', 'Reference' and/or 'Particulars' fields with your name, and whether the deposit is for donation, seminar or membership payment.

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.
© NZDPN 2022