

News+Views

Newsletter 75 – March 2016

The 2016 Seminar and AGM

The Network's Annual Seminar and AGM will be held in Rotorua on Saturday 7 May, 2016. The venue is the Sudima Hotel, 1000 Eruera Street, Rotorua 3010.



The Sudima Hotel offers accommodation. If you wish to stay on-site on the Friday and/or Saturday night please book directly with the hotel:
Tel: 0800 783 462 (toll-free) or +64 7 348 1174 (local number)
Email: reservations@sudimarotorua.co.nz

Registration Fee for attending the Seminar

For members: \$30.00 per person or \$45.00 per couple
For non-members: \$70.00 per person or \$90.00 per couple

Meals/ Food provided within Registration Fee:

Saturday – Morning and afternoon Tea, Lunch.

Other Meals:

Breakfast(s) and the Saturday evening meal (optional) are to be paid by attendees. We would strongly encourage you to attend the Saturday evening meal as this is an excellent time to mingle with other attendees.

The cost of the evening meal is \$42 per person and we have asked the hotel to seat our group in a separate room. If you are registering for the seminar please indicate whether you wish to join us for dinner. It will help us with planning if you include payment for dinner with your registration fee.

A registration form is included with this issue of the newsletter and can also be downloaded from www.dystonia.org.nz

We hope you can join us for this informative and supportive day where you can relax and share with others who genuinely understand what it means to have Dystonia.

Programme for NZDPN Seminar

- 9.15 Registration - Tea/Coffee on arrival
- 9.45 Welcome and introduction of Executive Committee by NZDPN Chairperson Alison Fitzpatrick
- 9.50 NZDPN Network Manager, Philippa Hooper will report on Network activities
- 10.00 Address by Dr Barry Snow
- 11.15 Short Break
- 11.30 Address by Julie Rope on the treatment of cervical dystonia
- 12.30 Lunch
- 1.30 Report from Dystonia Australia (their launch and subsequent progress)
- 2.00 Alison Fitzpatrick (her personal experience with DBS = deep brain stimulation)
- 2.15 David Barton (a report on the NSDA Conference in Chicago)
- 2.30 Patient panel discussion - 'Coping - What helps my dystonia?'

The programme is subject to confirmation and the times are approximate.

Note that the presenters are happy to take questions after their addresses, but please restrict these to general issues rather than your own diagnosis and treatment.

NZDPN Annual General Meeting

- 3.00 Declare AGM open (we will then adjourn for afternoon tea)

AGENDA

- Apologies
- Minutes of Previous AGM (9 May 2015)
- Financial Report
- Annual Report from Executive Committee
- Election of Officers
- General Business

Please note that all members are welcome to attend the AGM, but you need to be a financial member (paid subscription in the 2016 calendar year) in order to vote.

- 6.30 Dinner at Sudima Hotel (optional)

Speakers:

Dr Barry Snow is a neurologist and movement disorder specialist and is recognised internationally for his expertise in the management of movement disorders such as dystonia, and locally, he is a leading authority in patient care, advocacy and research.



Dr Snow was educated at Auckland Medical School and spent his first house surgeon year at Rotorua Hospital. After his FRACP examinations in 1983, he pursued geriatrics training before changing to neurology training at Auckland Hospital. Dr Snow left for Canada in 1988 to undertake his Neurolog-

ical Foundation V J Chapman Fellowship, and once completed, remained at the Movement Disorders Programme at the University of British Columbia in Vancouver as Associate Professor. During this time, he was engaged in research into movement disorders, and has since published well over 100 papers in this field. His research focus is centred on potential drug therapies for Parkinson's disease. Dr Snow returned to New Zealand in 1995 to join the Department of Neurology at Auckland Hospital before advancing to the position of Clinical Director of Neurology in 1999. In 2011 he was promoted to Medical Director, Adult Health Services at the Auckland District Health Board. He is a member of the Neurological Foundation Council. Dr Snow established the Auckland Movement Disorders Clinic in 1995 to lead a centralised structure

of specialists so patient care and research efforts in New Zealand could be optimised.

Julie Rope - Director & Senior Clinical Practitioner, Rope Neuro Rehabilitation

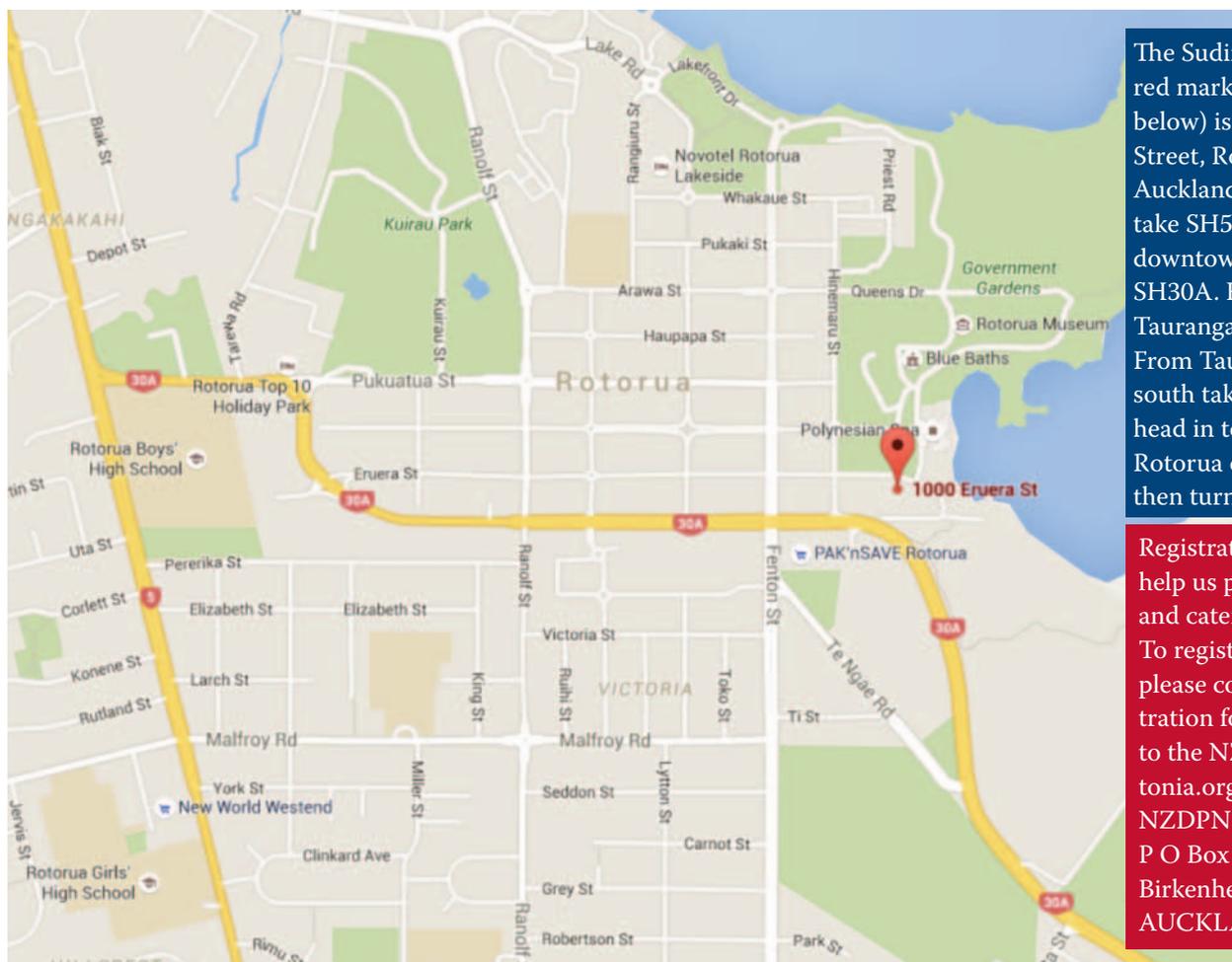
Julie graduated from Otago University in 1997 with a



Bachelor of Physiotherapy with Credit. Following junior rotations at Auckland Hospital she worked the next 6 years in England and Wales where she found her niche working in Neurology and Neurosurgery. On return to New Zealand Julie worked at Auckland City Hospital in the neurosurgical unit and providing

senior neurological support. Before setting up Rope Neuro Rehabilitation and OnlineNeuroPhysio to support the neurological client and clinicians looking for support.

Julie has had extensive experience within acute neurosurgical and neuromedical units, stroke rehabilitation units and community teams with both young and elderly client groups, neuro-intensive care units, a brain injury assessment unit for the minimally conscious, neuro-oncology and infectious diseases, vestibular clinics, neuro-hydrotherapy, spinal cord injury rehabilitation and Parkinson and Multiple Sclerosis community management.



The Sudima Hotel (see the red marker on the map below) is at 1000 Eruera Street, Rotorua. From Auckland and Waikato, take SH5 then head in to downtown Rotorua on SH30A. From Whakatane/Tauranga take SH30A. From Taupo and points south take SH5 and then head in to downtown Rotorua on Fenton Street, then turn right on SH30A

Registration in advance will help us plan for numbers and catering.

To register for the seminar please complete the registration form and send this to the NZDPN at info@dys-tonia.org.nz or by mail to: NZDPN

P O Box 34 259
Birkenhead
AUCKLAND 0746

Christchurch Support Group Meeting

Christchurch Support Group Leader Barb Murrell is planning to have an informal get together at her house, 16 McCormacks Bay Road, Mt Pleasant on Saturday 19th March at 11am. RSVP to her at 3842411 (leave a message on the answer phone), email barbsie98@hotmail.com or mobile 0272113884. A Farmers Market is held across the road from Barb's home on Saturday, from 9.30am, hence the extra traffic and a good opportunity to pay a visit if you wish.

Dystonic Tricks and Tips

A geste antagoniste is a physical gesture or position (such as touching your chin) which may serve to temporarily interrupt dystonic symptoms.

Some of the following sensory tricks / coping tips may be helpful. Anecdotally they help some patients, but not always consistently or long-term. Scientists believe these 'tricks' may distract the dystonia by altering feedback from the affected area - this fools the brain and prevents the inappropriate signals to the area concerned



Cervical dystonia or spasmodic torticollis

- Touching the chin, back of the head, neck, cheek or upper face gently can help with neck dystonia (torticollis) This touch is usually (but not always) more effective on the side of the head with the dystonia.
- Walking backwards
- Reclining or sitting with head support
- Resting the head against a wall
- Looking at a fixed point or into a mirror
- In a meeting choose a seating position carefully - often one end of the table works best if your neck is turning in a particular direction

Blepharospasm

- Press fingers against the temples, end of the nose, or other parts of your face – you need to find the spot that suits you
- Use a tight baseball cap, hair band or sweat band around the forehead
- Gum chewing, whistling, humming, talking, sucking on a straw or singing sometimes keep the eyes open in order to do activities
- Reading aloud
- Looking down (some people find gardening or cooking helpful because they involve looking down)
- Block out bright light - wear a baseball cap, golf visor, or sunglasses (especially the ones with thick sides which also cut out the wind)

Laryngeal dystonia or spasmodic dysphonia)

- Vocal exercise (humming, speaking slowly, reciting nursery rhymes)
- Using voice early in the morning

- Sensory gestures (covering eyes, pinching nose, holding the outside of the throat)

Oromandibular) dystonia

- Some people find activities like speaking and chewing reduce symptoms (for others they can make it worse)
- For jaw spasms – a toothpick, chewing gum, or sucking a boiled sweet has helped some people

Writer's Cramp

- Changing penhold / pen type
- Writing on a slanting surface as it can take the pressure off the wrist

Generalized / abdomen dystonia

- Tapping the foot slowly in a rhythmic way – was helpful to someone who had generalized dystonia and dystonia affecting internal organs
- Holding the chin, earlobe, and neck have helped with a person who has dystonia in the abdomen/trunk area

Paroxysmal dystonia

- Some people with Paroxysmal Dystonia found it very useful to keep a trigger diary to find out what may trigger attacks. Some types of Paroxysmal can be triggered by exercise, stress, caffeine, alcohol, tobacco, etc
- Another person found that changes in temperature may be a trigger, so they found that keeping feet warm in the winter and cool in the summer was helpful. If an attack occurs due to being overheated then applying cold flannel may be helpful.

Other tricks that may be helpful

- Squeezing the thumb and finger together rhythmically
- Squeezing the earlobe (or using a clothes peg)

Dystonia alert bracelet

Is it possible that you may end up in Accident and Emergency at hospital, and your dystonia may hinder communication with the medical staff? Perhaps your dystonic symptoms could be misinterpreted, or if you have spasmodic dysphonia you may not be understood clearly.

Wearing your dystonia medical ID bracelet and carrying the included wallet card can very valuable be in an emergency situation. The card provides important information about dystonia for medical personnel in emergency situations when you may be unable to communicate. There is room on the card to include personal information and your emergency contacts.

Bracelets are 316L Surgical Stainless Steel (Marine Grade) and can be worn at all times. They come in three sizes (all measurements are the circumference):

Large: 22 cm

Small: 19 cm

Child: 15 cm

To estimate your size place a paper ribbon around your wrist and mark the point where one end meets the paper again. Then measure.

The Network can offer these to members if there is sufficient interest to place a bulk order. The cost would be \$40 including packing and postage. Please email the Network at info@dystonia.org.nz with your details if you are interested or wish to place an order.



Update from the Chair

From Alison Fitzpatrick:

A very Happy and Healthy New Year to everyone and we hope you enjoy our first newsletter for 2016. A warm welcome to new members who have joined the Network over the last few months.

Earlier this month we emailed the annual invoice for 2016 membership fees to our members. A big THANK YOU to each of you who have made payment. When we all pull together it makes it possible to continue our work and to 'be there' for the newly diagnosed. We really appreciate your support because it makes a big difference to our modest financial situation.

We look forward to seeing as many of you as possible at our May seminar in Rotorua this year - it is closer than you think!

Generous grant

The Network wishes to acknowledge ongoing support from Allergan. Their assistance is tagged for 'administrative purposes', so helps with ongoing items like the P O Box, website, and other fees. The Network accepts Allergan's stipulation that we are under no obligation to recommend a particular product, and that there are no conditions that would interfere with our independence.

A big THANK YOU to all those who are able to support the Network's Mission. All contributions are welcome.

Dystonia Seminar in Sydney

Our congratulations to the volunteers who have relaunched the Australian dystonia group (DNA short for Dystonia Network of Australia) after several years in abeyance.



They are keen for an ongoing alliance with our Network and will try to get a couple of representatives to our Rotorua seminar.

Their website is dystonia.org.au

There will be a dystonia seminar in Sydney later this year. DNA are marking Dystonia Month (September) by holding it on Friday 2 September 2016.

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.

Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting.

Chairperson: Alison Fitzpatrick

Deputy Chairperson: Barbara Murrell

Secretary: Desiree Sargon

Treasurer: David Barton

Committee Members: Roger Terry, Alex Weir

Network Manager: Philippa Hooper



Left to right: Roger Terry, Alison Fitzpatrick, Barbara Murrell, Philippa Hooper, Des Sargon

NZDPN phone number: (06) 364 7618

NZDPN email: 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 \$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 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


New Zealand
Dystonia
Patient Network Inc.
www.dystonia.org.nz
Email : info@dystonia.org.nz

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