

National and international news and views  
Networking Dystonia patients



# News+Views

Newsletter 72, March 2015

## 2015 SEMINAR AND AGM

### WHERE:

Cornwall Room, Surrey Hotel  
465 Great North Road, Grey Lynn, Auckland, NZ

### WHEN: 9 MAY 2015

The Cornwall Room is at ground level, so is suitable for wheelchair access if required.

The Surrey Hotel offers accommodation.

If you wish to stay on-site on the Friday and/or Saturday night please book directly with the hotel:

Tel: (9) 378 9059 Fax: (9) 378 1464

Email: [reservations@thesurreyhotel.co.nz](mailto:reservations@thesurreyhotel.co.nz)

Registration Fee for attending the Seminar:

The registration fee is \$30.00 per person  
or \$45.00 per couple.

Please find a registration form included  
with this newsletter.

Meals/ Food provided within Registration Fee:

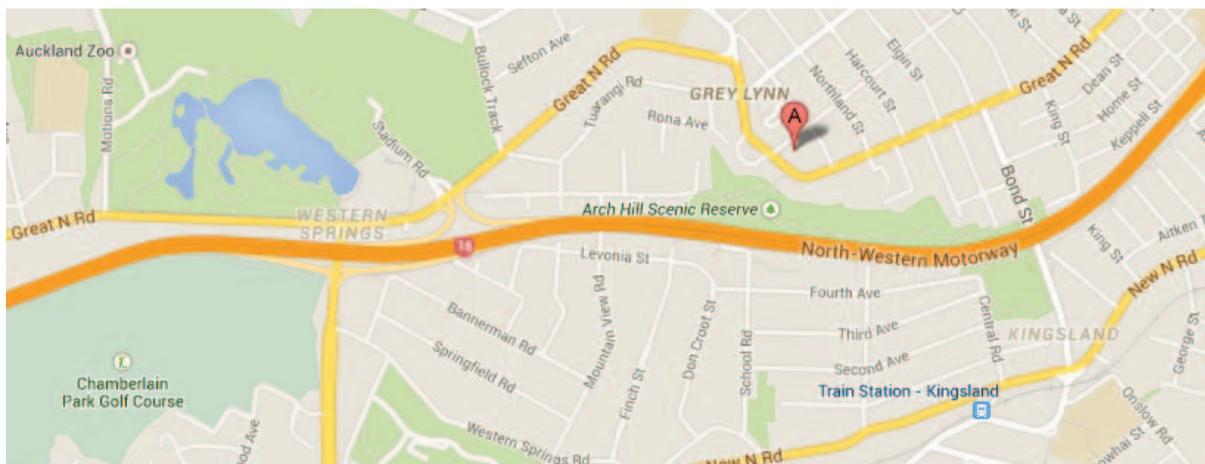
Saturday – Morning Tea, Lunch, and Afternoon Tea



Other Meals:

Breakfasts and the Saturday Evening Meal 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.

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 (subject to confirmation)

- 9.30 Registration - Tea/Coffee on arrival
- 10.00 Welcome and introduction of Executive Committee members by NZDPN Chairperson
- 10.05 NZDPN Network Manager, Philippa Hooper will report on Network activities during the past year.
- 10.30 Address by Dr Mark Simpson
- 11.20 Short Break
- 11.30 Address by Dr Gerard Deib
- 12.20 Lunch
- 1.20 Address by Julie Rope (neurophysiotherapist from Rope Neuro Rehab.)
- 2.10 Patient panel discussion - 'Coping - What helps my dystonia?'

*Please 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

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

## AGENDA

- Apologies
- Minutes of Previous AGM (17 May 2014) and Special General Meeting (23 September 2014)
- Financial Report
- Annual Report from Executive Committee
- Changes to the NZDPN Constitution
- Election of Officers
- General Business



## 2015 Seminar Guest Speaker Profiles

**Dr Mark Simpson** is a neurologist with special expertise in the management of movement disorders. Dr Simpson was trained in Auckland, Melbourne, London and Toronto.

**Dr Gerard Deib** is a sub-specialist neuroradiologist, and an expert on medical imaging and image-guided therapies in the diagnosis, management and treatment of dystonic symptoms.

After completing his medical degree at the University of Witwatersrand, Johannesburg, he obtained membership of the Royal College of Surgeons (Edinburgh) and fellowship of the Royal College of Radiologists (London). Gerard moved to Auckland after completing a neuroradiology fellowship at the University of Virginia and a combined research and clinical fellowship at Johns Hopkins, where his research focused on functional



brain imaging (including fMRI and PET). Gerard also works at Mercy Radiology Group.

**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 neurological clients and clinicians looking for support.



Julie has had extensive experience within acute neu-

rosurgical 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.

## Update from the Chair

*From Alison Fitzpatrick:*

Greetings everyone and welcome to our first newsletter for 2015. We are currently in the process of finalising our speakers for our seminar in May. We hope to see many of you there on the day. It looks as though it is going to be extremely interesting and informative.

At this time of the year we post out our invoices for the annual subscription/membership fee. We really appreciate your support because it makes a big difference to our modest financial situation.

We thank those who are able to make a contribution.



## Auckland Support Group meeting

Faye Bagosi and Alex Weir very kindly hosted a support group meeting at their lovely home in Hillsborough on Saturday 15 November. About 16 members attended altogether.

*Ex-Chair  
Dave Mitchell and  
Richard Symonds*



## Christchurch Dystonia Support Group Gathering

From Barb Murrell: "I am planning to have an informal get together at my house, 16 McCormacks Bay Road, Mt Pleasant on Saturday 28th March at 11am. You are all welcome to come along for a chat and catch up. RSVP to me at 384 2411 (leave a message on the answer phone) or (027) 211 3884 or email: barbsie98@hotmail.com.

A Farmers Market is held across the road from my home on Saturday, from 9.30am, hence the extra traffic and a good opportunity to pay a visit if you wish."

## Changes to the Network's Constitution

The Executive Committee are proposing some changes to the Network's Constitution. Please see the Network's website [www.dystonia.org.nz](http://www.dystonia.org.nz) for an outline of the proposed changes. The current Constitution is also provided there for your reference.

The Network is also posting the outline of the changes to all 2015 Financial Members.

## Dystonia Symposium in Adelaide

The newly reconstituted Australia Dystonia Group are co-hosting a symposium in Adelaide this May together with Parkinson's Australia. The dates are 27-29 May 2015 and the venue is Riverbank Rooms, Adelaide Convention Centre, North Terrace, Adelaide, SA, Australia

*Sessions on dystonia include:*

- The causes of dystonia (Dr Florence Chang, Westmead Hospital, Sydney)
- Neurological conditions affecting the function of the hand and cervical region (Jean-Pierre Bleton, Rothschild Foundation, Paris)
- Environmental factors in dystonia (Dr Caroline Tanner, University of California, San Francisco, CA)
- Non-invasive brain stimulation as a novel treatment for cervical dystonia (CD) and a dystonia-specific scale to measure kinesiophobia (movement avoidance) (Dr Lynley Bradnam, Flinders University, Adelaide)

For more information please see <http://www.aomevents.com/ParkinsonsAustraliaNationalConference/Registration>

The Network Manager has information about accommodation options if you are considering attending. Please email [info@dystonia.org.nz](mailto:info@dystonia.org.nz).



  
New Zealand  
**Dystonia**  
Patient Network Inc.  
[www.dystonia.org.nz](http://www.dystonia.org.nz)  
Email : [info@dystonia.org.nz](mailto:info@dystonia.org.nz)

## The NZDPN is governed by an Executive Committee, elected each year at the Annual General Meeting

Chairperson: (Acting) Alison Fitzpatrick  
Secretary: Desiree Sargon  
desiree.sargon@roche.com  
Treasurer: (Acting) David Barton  
dsbarton@ihug.co.nz  
Network Manager : Philippa Hooper  
phooper@paradise.net.nz  
Committee Members: Roger Terry, Barbara Murrell

### Other positions

E-mail Contact and Information Officer:  
Alison Fitzpatrick  
alisonfitzpatrick@yahoo.com.au  
Webmaster and Database Manager:  
David Barton  
dsbarton@ihug.co.nz

### To contact the Executive Committee by mail please write to:

Executive Committee  
New Zealand Dystonia Patient Network  
PO Box 34 259  
Birkenhead  
Auckland 0746

### Donations and membership:

The NZDPN is a Health Promotion Association registered with the New Zealand Charities Commission. 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 for the calendar year in which the payment is made. Donations are also welcome and are tax deductible.

#### Internet Banking details are:

NZ DYSTONIA NETWORK  
ANZ BANK, WAIKANAE  
06-0577-0110415-00

Please complete the 'Code', 'Reference' or 'Particulars' fields to let us know whether a deposit is a donation or membership. If you wish to send a cheque our address is:

The Treasurer,  
New Zealand Dystonia Patient Network  
PO Box 34 259  
Birkenhead  
Auckland 0746

PLEASE NOTE - Receipts will be automatically issued for amounts of \$100 and over. Receipts for lesser amounts will only be issued upon request.

Support Group Leaders can be contacted by Emailing [info@dystonia.org.nz](mailto:info@dystonia.org.nz) or contact details are available on our Web-site [www.dystonia.org.nz](http://www.dystonia.org.nz), (Charities Registration: CC10565).

### New Twitter account

Did you know that the NZDPN has a social media presence? We are on Twitter. Our handle is @NZDPN.

Twitter is a great way to read and share information online. Registered users can both read and post tweets and non-registered users can read them but not post anything. This means that users have a measure of control over their own privacy, which is often a good thing when looking for information on medical conditions. Check us out at <https://twitter.com/nzdpn> and help make #Dystonia and #DystoniaAwareness trending topics!



### 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 general public
- To encourage and facilitate research, with the aim of seeking better treatments, prevention, a cure

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#### Disclaimer

The NZ Dystonia Patient Network Inc provides information in this newsletter as general information only. It is not intended to provide instruction and you should not rely on this information to determine diagnosis, prognosis or a course of treatment. It should not be used in place of a professional consultation with a doctor.

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### Letters to the Editor

We welcome your comments. Please forward to Shirley Henderson : email [newsletter@dystonia.org.nz](mailto:newsletter@dystonia.org.nz)

We acknowledge and thank Allergan and NZ Lotteries, for their financial support.