

# News+Views

Newsletter 73 – July 2015

## Highlights of the 2015 Annual NZDPN Seminar

The Seminar was well supported, with about 40 people in attendance. We were pleased to welcome a delegation from the NZ Essential Tremor Support Group. Afterwards they said how valuable the experience was. We look forward to continued close links with this group.



All three presentations by the invited professionals were well received. Dr Mark Simpson gave an overview of dystonia, Dr Gerard Dieb talked about medical imaging, and Julie Rope covered physiotherapy and related topics from a neurological perspective. Thanks to all.



Dr Gerard Dieb with Philippa Hooper

## Neurological Fatigue Management

Below is a summary of the main points from a talk by Julie Rope, of Rope Neuro Rehabilitation, given in Napier on 14 July, attended by Committee member Roger Terry and Grace Terry. Many of the symptoms of dystonia are physically exhausting and mentally draining. Our thanks to the Terrys for passing on this advice.

### General Points about managing fatigue

- Any small changes made can accumulate
- No challenge = no change
- Fatigue is not the same as tiredness
- It is unpredictable, one can “hit a wall”

### Physical fatigue vs. Mental fatigue

- Type of resting is different for each type
- Need for increased self-management
- Energy expenditure is like a phone battery that runs down
- Physical rest is watching TV, reading etc
- Mental rest is NO electronics, but instead meditation, sleep, breathing exercises
- Take 5 – 15 minutes wherever you are
- Take short rest periods through the day
- Have a cold glass of water; breathe prior to a meeting
- Take ½ hour prior to having visitors
- Schedule your resting, e.g. 2 hours. No need to lie down.
- Do tasks smarter, break down into small steps
- Food shop “on-line”
- Position well for tasks, e.g. food preparation at dining table or use a “perch” stool
- Buy pre-cut vegetables
- Plan meals weekly
- Arrange a “uniform” for each day of the week
- Ensure there’s always something in the freezer
- Turn off the radio in the car.

### Advice - the four D's

**Ditch** - those things that are energy wasters

**Do** - those things you love to do

**Delegate** - things to someone else

**Delay** - wait until you have more energy

### Exercise

- Need at least 30 minutes/day of cardiovascular exercise
- This assists circulation, pain, neurological health, strength, bone health, and fatigue.

Source: Rope Neuro Rehabilitation – Julie Rope  
[www.onlineneurophysio.co.nz](http://www.onlineneurophysio.co.nz)

## Advances in ultrasound techniques

One of the most interesting areas covered by Dr Dieb in his presentation was speculative - about the possibilities of using ultrasound in the future to make beneficial alterations to the brain in people with neurological disorders.

At present any interventions are invasive - they involve accessing the brain through the skull - for example deep brain stimulation (which is a known procedure and helps some dystonia patients) involves cutting a hole in the skull first and then inserting a probe.

In contrast, ultrasound can focus the energy of sound waves (similar principle to using a magnifying glass to focus the sun's energy at a particular place).



This procedure is already used by gynaecologists to deal with fibroids in the reproductive organs. Now a company in Israel (Insightec) has been experimenting with ultrasound to the head. A patient wears a special helmet with sound transmitters fitted on the inside lining. These transmitters are carefully calibrated and focused to deliver sound energy to a very specific region in the brain.

## Alcohol Responsiveness in Laryngeal Dystonia: A Survey Study

Dr. Kristina Simonyan and her research team at the Icahn School of Medicine at Mount Sinai, New York, conducted an on-line research study to investigate the effects of alcohol on symptoms of dystonia and tremor in a large population of patients. They have recently published the results of this survey and below is the lay summary.

Authors: Diana N Kirke, Steven J Frucht, Kristina Simonyan  
The full article on this study was published in the Journal of Neurology (2015): May 1

### Lay summary of research

It has long been noted by patients and physicians alike that alcohol improves the symptoms in many patients with spasmodic dysphonia (i.e. laryngeal dystonia). However, this anecdotal finding has never been confirmed. Thanks to the NSDA community, we were able to survey 641 patients with

isolated spasmodic dysphonia (SD, or laryngeal dystonia) and with spasmodic dysphonia combined with voice tremor (SD/VT). We found that more than half of patients in both groups thought that their voice symptoms improve to some extent after drinking alcohol. Patient's family and friends also noticed similar improvement. The duration of effect of alcohol on voice symptoms was thought to last 1 – 3 hours in both patient groups. Although alcohol is an interesting and potentially powerful agent, the results of this survey study do not imply or recommend alcohol consumption in any form in order to treat SD symptoms. However, this information may help us, the researchers, to start thinking about new and alternative pharmacological agents with effects similar to alcohol in order to develop more efficient treatment options for SD and other dystonias.

## Area Contact Persons – an initiative from the NZDPN

The Network has set up a list of 'Area Contact Persons (ACPs)'. These people have volunteered to be contacted by other dystonia people. When the Network receives an inquiry from a new patient either living in their area, or with their type of dystonia, the Network gives the new patient the ACP's contact details. The list of Area Contact Persons can be viewed at [www.dystonia.org.nz](http://www.dystonia.org.nz).

If you would like to volunteer for this role please indicate your interest to the Network. We emphasise that this is completely voluntary, and you can withdraw your permission at any time.

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

## Annual 2016 Seminar

Please save the date for our annual seminar. The Committee are currently planning the programme.

The actual date is likely to be Saturday 7 May, and we are looking at Rotorua as the venue. Please do not make travel arrangements until confirmed.



Further details will be published in our next newsletter, and also announced at our website [www.dystonia.org.nz](http://www.dystonia.org.nz)

## Disputes Tribunal Decision

The Network recently brought a case in the Disputes Tribunal against ex-Treasurer Chriss Spooner. The most substantive part of the case involved a payment by Mrs Spooner to herself for travel to a Network Seminar in May 2013. This payment was unknown to the Committee at the time, was not discussed and was unauthorised. This matter first came to light when Mrs Spooner returned financial records to the Committee in October 2014 (several months after she resigned).

Mrs Spooner was ordered by the Tribunal to repay \$560.45 to the Network. The following is an extract from comments made by the referee in the judgement against Mrs Spooner:

“The position of Treasurer is one that involves considerable trust. The Treasurer therefore has a duty to ensure that they can account for all their actions and that their actions are transparent. This is particularly important when money is being paid to the Treasurer by the Treasurer. The prudent person would ensure that they obtain clear approval before accepting funds.”

“Having considered the above, I find that Mrs Spooner has failed to follow an accepted or prudent practice by paying Network funds to herself without first seeking the approval of the Committee. As Mrs Spooner did not have authority to withdraw the funds, I find she is liable to refund the full amount”.

Mrs Spooner was also ordered to compensate the Network for a stop fee charged by the ANZ Bank:

“Mrs Spooner advised the bank (two weeks after she resigned) to stop the accounts. However at the time, Mrs Spooner was not the Treasurer and had no authority to act on behalf of the Network”.

## Update from the Chair

**From Alison Fitzpatrick:**

Greetings everyone and welcome to our second newsletter for 2015. We were delighted to see many of you at our Annual seminar in May.

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.

## New Committee member

The Committee are delighted to welcome Alex Weir, of Auckland, as a member.



*Alex Weir, new NZDPN Committee member*

Alex is a long-time supporter of the Network, hosting several Support Group meetings together with his partner, Faye Bagozi, in their home in Hillsborough. Many of you will know Alex through the Auckland Support Group and will have met him at our annual Seminars.

## Changes to the Network's Constitution

The Executive Committee proposed some changes to the Network's Constitution as publicised in the previous Newsletter. All changes were passed unanimously at our 2015 AGM. Please see the Network's website [www.dystonia.org.nz](http://www.dystonia.org.nz) for the updated Constitution.

The Constitution, together with the Certified Minutes of the AGM have been uploaded to the Charities Commission website as per their regulations.

## 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](mailto: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 over \$100, and otherwise on request. Donations are also welcome and are tax deductible if \$5 or over.

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

## 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 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.*

  
New Zealand  
**Dystonia**  
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