



News+Views

Newsletter 89 – March 2021



In Memoriam – Philippa Hooper



It is with great sadness but also a sense of gratitude that the Network acknowledges the lifetime contributions of Philippa Hooper. Philippa initially served as Treasurer and later as Network Manager until 2019. As one of our founding officers she was determined and

tireless in her work to support, encourage and seek answers for family, friends and complete strangers. In most people's lives they are only truly influenced by several dozen others, and Philippa was one of these - always positive, motivated, a close confidant and driven by a desire to help others. She will be greatly missed. Farewell Philippa, and thanks for the memories.

NZDPN Seminar: Saturday 22nd May 2021

This year's Seminar is being held in Wellington at the Brentwood Hotel on Saturday 22nd May.

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 Brentwood Hotel is close to the Kilbirnie shops and the airport. For out-of-town guests there is a free 24-hour airport shuttle service; for pick up call freephone 0508 273 689.

If you wish to stay on-site over the weekend, please book directly with the hotel;

Phone: 0508 273 689 (0508 BRENTWOOD)

Email: reservations@brentwoodhotel.co.nz

Website: <https://www.brentwoodhotel.co.nz>

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 Wellington. It is available to 2021 financial members (current as at 31 March 2021); and who live in the South Island, or Palmerston North and Masterton northwards.

Just book and pay for your room as usual, then for reimbursement submit your hotel receipt for either the 21st or 22nd of May 2021 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 – 22nd May 2021

'In honour of Philippa Hooper'

The Seminar this year is dedicated to the memory of Philippa Hooper. We hope you can join us for this informative and supportive day where you can relax and share with others who understand what it means to have Dystonia. Please note that the programme is subject to confirmation and times are approximate.

- 9.00 Registration - Tea/Coffee on arrival
- 9.30 Welcome and introduction of NZDPN Committee, Chair Alison Fitzpatrick
- 9.45 Dr David Bourke – Dystonia 101
- 11.00 Short Break
- 11.15 Shona Daube – Coping strategies for living well with chronic illness
- 12.00 Sharing memories of Philippa Hooper
- 12.30 Lunch
- 1.30 TBA
- 2.15 Alison Fitzpatrick – Understanding the benefits of Tai Chi
- 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 2021 financial member in order to vote.

Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting. The Committee for 2020/2021 is;

Chair: Alison Fitzpatrick

Secretary: Desiree Sargon

Treasurer: David Barton

Network Manager: Dave Mitchell

Committee Members: Jayne Lewington Lovell, Gabbie Carruthers, Elizabeth McPherson

The network is always in need of members to assist in dystonia projects. If you have some spare time please come and join us. Contacts are info@dystonia.org.nz or 0508 397 866.

Evening Programme

- 6.30 Buffet dinner at the Brentwood 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 David Bourke



Dr David Bourke is a New Zealand trained neurologist who works in Wellington, the Hutt Valley and Wairarapa. He trained in Auckland, then did a fellowship at the National Hospital for Neurology and Neurosurgery in London. David is a general neurologist with an interest in movement disorders, including dystonia.

Shona Daube



Shona Daube is a Community Advisor in the Wairarapa region, for the Wellington MS Society. Six years ago she was diagnosed with multiple sclerosis. With a nursing background, Shona is familiar with the challenging aspects of chronic health conditions like MS. She is passionate about living her life to the fullest and empowering others to do the same. As well as her work for the Society, Shona has written three books, and received a 'Local Hero Medal' in the 2020 New Zealander of the Year awards.

Alison Fitzpatrick



Alison is our esteemed NZDPN Chair. She also holds a black belt in Tai Chi, and has discovered enormous physical and mental benefits from practising this ancient Chinese art form. As a walker (and sometimes runner), Alison believes that dystonia need not be a barrier to enjoying a variety of activities. After ten years of studying, Alison is now working towards a 2nd degree black belt and her dream is to eventually teach Tai Chi.

Medicinal Cannabis – Dr Shaun Holt

The Network is regularly asked for information on the use of medicinal cannabis to alleviate dystonia symptoms. Below is a summary of an article by Dr. Shaun Holt. For the full article go to our website; <https://www.dystonia.org.nz/>

Dr Holt holds Pharmacy and Medicine degrees, and is author of the book *Medical Cannabis: a brief guide for New Zealanders*.

In New Zealand cannabis is legal for medical purposes; but in practice, few products are available, they are expensive and only a small number of doctors prescribe them.

There have been hundreds of studies of cannabis for many medical conditions, but other than for pain and nausea there is a lack of proof that it is effective. However, given the large number of people who use it for medical purposes, in my view it is only a matter of time until it is proven to be safe and effective for a variety of conditions.

Some people are not aware that we all have cannabis chemicals naturally in our bodies, called endocannabinoids. They are a normal part of the way our body regulates itself. This is an important point: yes we can ingest cannabis products containing cannabis chemicals (called cannabinoids), but they are already there in the body. It is the same with steroids, as we can take steroid medications and these supplement the steroids that our bodies naturally produce. Cannabinoids are involved in the regulation of many bodily systems including: pain, immune response and sleep. The endocannabinoid system also modulates neurotransmission involved in motor function and some studies have shown that it can help with some disorders of muscles and movement.

For example:

- Tremor, rigidity and bradykinesia in Parkinson's disease
- Spasticity in multiple sclerosis (MS)
- Motor and vocal tics in Tourette syndrome

So, can cannabis help people with dystonia? Some factors to consider before trying are:

• **How effective and are standard treatments**

If existing treatments work well and do not have significant side effects, then it is probably not worth trying cannabis. However, there are diseases which do not have good treatments, or they have terrible side effects. In these cases trying cannabis could be better than what is on offer.

• **What happens when you try it**

No treatment works for everyone; we are all different and so there is certainly merit in trying cannabis to see if it helps. This trial and error approach may not be scientific, but it is often the way that doctors manage their patients. It is possible when doing this trial, to believe that cannabis works when maybe it does not, due to factors such as the placebo effect or the natural history of the symptom. On the other hand, if there is no apparent benefit then at least the person knows they have tried it, and decide it is not for them.

• **What are the potential benefits and risks**

There are always risks and benefits when using any medical treatment. The risks of cannabis may outweigh the potential benefits, especially if it is smoked and could cause lung cancer if inhaled in large amounts over several years. But on the whole it is safe and any risks should be considered alongside any improvements in quality of life.

To conclude, if I had dystonia, would I try medical cannabis to see if it helped – Definitely!

References:

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From the Chair – Alison Fitzpatrick

Nau mai, haere mai ~ I recently took part in a women's 10km "fun" run at the Villa Maria Estate in Auckland. The purpose of the run was to raise money for the Look Good, Feel Better charity, and to empower women to challenge themselves physically and mentally.

I have never been a natural athlete and running with dystonia poses certain challenges. Each of us experiences dystonia in a different way. For me, the hardest part about running is dealing with muscle spasms in my feet. I have found however that the benefits to my overall health outweigh the costs, so, on I travel!

Running gives you time to think, and during the Villa Maria run, I thought a lot about Philippa. How she never gave up, and how she chipped away at the health system in her advocacy for both her biological and dystonia family. I felt Philippa with me during the run particularly during the 7th and 8th kilometre when I "hit the wall" and felt like giving up. I told myself that I needed to put one foot in front of the other, just like Philippa did with her dystonia advocacy, and I would get there in the end. And before I knew it, I had crossed the finish line. It may not have been pretty, but I did it!

We look forward to seeing you at our May seminar. Take care and be kind to yourselves.

Neurological Alliance

The Network is pleased to report that our group was recently invited to join the Neurological Alliance. This Alliance is a partner of The Neurological Foundation which was established in 1999, to provide a forum for organisations representing a neurological disease to work together on matters of common interest.

It is exciting to be part of a bigger network with similar aims to the NZDPN. Joining the Alliance gives a stronger voice in raising community awareness of neurological diseases. There will also be a collective effort to ensure that people with neurological conditions have the best possible quality of life.

Dave Mitchell has agreed to represent us and is in regular communications with the Alliance. This year for instance he will be present at four Zoom meetings, and will report back on any points of interest.



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 to let us know your name, and whether a deposit is a 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.

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