National and international news and views
Networking Dystonia patients

New Zealand Dystonia Patient Network Inc.

News+Views

Newsletter 94 – January 2023 • Contact us: 0508 397866 or info@dystonia.org.nz • Donations are welcome

Message from the Chair – Alison Fitzpatrick

Kia ora koutou, warm summer greetings to you all. After such a stormy and soggy start to the year, many of us are left wondering what else 2023 might have in store for us. However, our community of Dystonians is resilient. If anyone can deal with adversity, it is us!
Stay safe and go well.

NZDPN Annual Seminar

This year's Seminar is to be held at The Sudima Hotel, Christchurch Airport, on 17 June. All members are invited to attend. This is a great opportunity not only for networking and companionship but to also hear from a learned and expert line-up of speakers to be advised in our next newsletter along with a registration form and the programme for the day.
The Sudima is very close to Christchurch Airport, has a complimentary shuttle service, parking and wheelchair access, amongst other facilities.

Rare Diseases NZ Hui

Our Committee member Jayne Lewington-Lovell represented the Network at a function in Wellington last year. Here is her report.
On Friday November 11th 2022, Rare Disorders NZ hosted a one-day Hui for support group leaders to meet with others in the rare disorders community.
I went down to Wellington to represent our dystonia group and as an opportunity to air the needs of those with rare disorders to be included in the restructuring of the health system. There was an interesting mix of groups with some I knew of like Fragile X Syndrome and Spinal Muscular Atrophy. And some not known like Fabry Disease, and UNIQUE which is a UK-based group for those with rare chromosome and gene

Attendees at Hui

disorders. For conditions like Fabry there were only the family members affected; but for those with Prader-Willi Syndrome (a neurodevelopmental disorder), there are approximately 140. The most similar to our group was the Mal de Débarquement Syndrome (MdDS). MdDS is a neurological disorder of perceived movement manifesting as a constant feeling of rocking, bobbing, or swaying which seems to be alleviated in passive motion such as riding in a car.
There were about forty of us present on the day and presentations included the;

- basics of Social Media
- input of consumer advisory groups in the new health reforms from the Health Quality & Safety office
- advocacy services provided by the Health & Disability Commission

It was heartening to hear that more input from consumer advisory groups is being included in the new health reforms. This is to address inequalities in the present system. It is hoped by incorporating the lived experiences of those accessing healthcare, treatment may be more consistent and based on need, rather than by postcode. Also heartening was discussion on the strengthening of the Health & Disability service and most particularly their role as patient advocates.
We then enjoyed a delicious afternoon tea of cupcakes!

The last session was for ideas to mark Rare Disorders day in 2023. Rare Disease/Disorder Day is celebrated each year around the world on the last day of February (the rarest day of the year) to raise awareness and to advocate for equity for rare disorders. New packs are being put together by Rare Disorders to be shared on social media, or with medical practitioners or as part of a presentation.

It was a busy day but enjoyable and good to be back at the Brentwood Hotel again. Rare Disorders are considering making the hui an annual event as it was a great opportunity to connect up with others. My final words are for all the workers at Auckland and Wellington airports who assisted me and my walker between the two cities. To the terminal and Airline staff my deepest appreciation for your kindness especially those pushing the wheelchairs; and to Air New Zealand for checking in my walker free of charge. Without the support of these folk, people like us would find it difficult to travel at all.

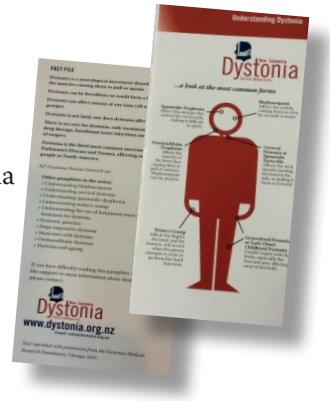
And a big thanks to Rare Disorders for hosting this event and assisting our Network to attend the Hui.

RARE DISEASE DAY®

NZDPN Pamphlets

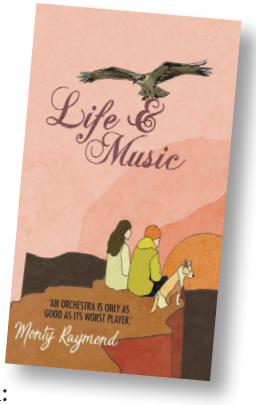
Your Network has a range of pamphlets, listed below, available for distribution. Should you require any of these, either for yourself or for your Health Professional, we will be happy to send these out.

- All about the NZDPN
- What is dystonia?
- Frequently asked questions: Prognosis
- Frequently asked questions: Causes and Treatments
- Frequently asked questions: Symptoms
- Understanding the use of Botulinum Toxin in the treatment of dystonia
- Oromandibular dystonia
- Understanding writer's cramp
- Understanding blepharospasm
- Understanding spasmodic dysphonia
- Understanding cervical dystonia
- Children with dystonia
- Musicians with dystonia
- Dystonia and aging
- Deep brain stimulation
- Dopa-responsive dystonia
- Dystonia: genetics
- Understanding dystonia: per photo, a single page pamphlet, very handy for distribution to your GP or other medical specialists.



Disabled Country – Neil Marcus

If there was a country called disabled,
I would be from there.
I live disabled culture, eat disabled food,
make disabled love, cry disabled tears,
climb disabled mountains and tell disabled stories.
If there was a country called disabled,
I would say she has immigrants that come to her
From as far back as time remembers.
If there was a country called disabled,
Then I am one of its citizens.
I came there at age 8. I tried to leave.
Was encouraged by doctors to leave.
I tried to surgically remove myself from disabled country
but found myself, in the end, staying and living there.
If there was a country called disabled,
I would always have to remind myself that I came from there.
I often want to forget.
I would have to remember…to remember.
In my life's journey
I am making myself
At home in my country.



Life and Music Novel

The long awaited novel Life and Music is now available for order in eBook format. It is also available as a paperback.

From the Author's wife, Margot Chiverton:

"I hope you enjoy this fictionalised account of my dystonia journey, created by my husband under the name Monty Raymond."

The story: In the only world she's ever known and wanted, Cecelia Cavendish lives her dream, playing principal bassoon in an orchestra with her best friends, Annie and Fleur. But when a mysterious ailment grips her body one night during a concert, Cecelia's future changes forever. Suddenly she's forced to confront prejudice and stigma, alone. Her career's at stake, and Sebastian, the man she loves as much as her music, is walking out the door. Does she have the strength to save what she loves, or ultimately, accept her fate?

Please leave a review on the sale website to encourage readers to learn about dystonia.

Classification guide: Recommended for mature readers.

Order your eBook online or purchase from a bookshop.

A portion of profits from sales will be donated to dystonia research and support.

Related link: Short Film 'Dystonia': Dystonia by Peter at Corgipawfilms - YouTube and DYSTONIA (with subtitles) by Peter at Corgipawfilms (CWCFILMS) in Australia - YouTube

Thank you to all for your wonderful support,
Margot Chiverton xx

Dystonia: one patient's surprising adventure to help find answers to doctors' questions

In 2016, something went wrong. I was in my sixties, a retired teacher, married, 4 kids, 7 grandkids.

Beverley Smith (a retired schoolteacher in Calgary, Canada)

In the spring I got a shingles vaccine. Over the next 9 months, a strange virus went through me. I had stringy phlegm, stomach cramps and headache. I got cracks in my skin that would not heal and they became infected. My coughing fits were intense. My doctor ordered a chest X- ray, blood tests and lung function tests (all normal) and prescribed me antibiotics. He said it would pass but, just in case, I updated my will.

By fall, I had a stinging purple rash and was losing weight. Not sleeping well, I was frustrated and asked for help for anxiety. I was eventually put on Venlafaxine, Respiridone, Clonazapam and Aur-Mirtazapine, all at the same time, and told to stay on them a year. But, on these medications, I developed facial grimaces, tics and lip smacking, becoming my own morphed nightmare in the mirror. It was hard to hold my head down on a pillow. I'd shift at night every 90 seconds to find a position with less pain. On the plus-side, my mood was improving. I now hoped to live. However, my head felt like someone was pushing me hard against a wall to tilt left. I was keen to taper off the pills and that magic day arrived in December 2017. Nearly immediately the grimacing stopped. I had a wonderful new doctor who told me clearly how to wean myself off the pills and the secret was to do it slowly. It would take a year.

My pharmacist suggested I go to a movement disorder clinic and a physiotherapist suggested a neurologist. I was amazed. The medical profession really is a fraternity, all trying to help. The referrals were a great idea. I was diagnosed with cervical dystonia.
By January 2019, off the pills, I felt hope again. The virus was gone but dystonia was a new chapter. Pain pills made me dizzy and after receiving botulinum toxin injections, I developed problems swallowing.
I wondered if it was just my genetic make-up that made me so sensitive to treatments.

As a longtime substitute teacher, at K-12 level, I supposedly know how to handle crisis. My pride had to take this on. I researched dystonia on the Internet, bought six biographies of people who had it, read movement disorder textbooks and clinical studies posted online. I joined a support group, went to meetings, attended a conference in Vancouver, and joined Facebook groups. I took notes.
I learned that for some patients with dystonia, muscles had tightened in a finger and they could not play piano. For some it was in an arm and they could not golf, in a leg and they could barely walk, in the eyelids and they could barely see, in the vocal cords and they could barely talk. All shockingly odd – and incurable – conditions. Some patients developed it after injury, some after overuse, some had it from birth, or mysterious unknown causes. Most of us at diagnosis had never heard of dystonia. It had stigma, ended careers of radio announcers, clarinetists, baseball players and was usually visible to strangers. I learned it has existed for centuries, even in medieval paintings.

How could I help – me with no medical training? Well, I excel at making lists. I know how to ask questions. Clinical studies often commented that more needed to be learned about symptom progression, sensory tricks, effect on daily life. And in this corner, in the blue trunks, we patients also were mystified. Does anyone else have ear pain? Maybe I could collect anonymous experiences of patients and see if there were patterns like researchers were asking about – we patients could tell what we know of this condition.

I set up a website, "Lived Experience with Dystonia" and, through Survey Monkey, posed questions. Lots of questions. Anything I'd flagged in my reading. I was now in touch with patients in Israel, New York, Toronto, Calgary, Nova Scotia, Australia, England and Wales and felt an affection for them like family. I was in awe of some who have had dystonia for twenty years. There is wisdom there.
A fellow patient, a church minister in the US, suggested I not bombard the world with 1,500 questions but break them up into short optional surveys and provide a basic quick survey option. Great ideas. The project would last for one year. I needed time to find people to ask and they needed time to wade through the questions.

It is done. Over 1,800 surveys were completed.
The website has been viewed in 83 countries. It was heartwarming in a hands-across-the-world way.
We patients know that alone we can do nothing but together, hey, this may help.

The complete results of my surveys are available on my website.
For a limited time only because, hey, I'm in my seventies and I will be taking the website down eventually.
Feel free to download.

Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting. The Committee for 2022-23 is
Chair: Alison Fitzpatrick
Secretary: Desiree Sargon
Treasurer: David Barton
Committee Members: Jayne Lewington-Lovell and Dave Mitchell.
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. 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.

Area Contact Persons

As you are no doubt aware, we have a nationwide list of members on our website who have various forms of dystonia and have agreed to be contactable by email to offer support to other members, usually local.

We find this works well as it isn't always feasible to hold Support Group meetings, but we want to offer the option for personal contact locally.

If any members are interested in joining this network, simply send an email to info@dystonia.org , we would love to hear from you!

NZDPN P.O. Box

We have had to close our P O Box due to rising costs and a definite lack of activity, the cost certainly did not warrant keeping it open.

News and Views Newsletter

As we are well and truly into the digital age we are letting our membership know that if people are prepared to receive the newsletter as a PDF let us know, again on info@dystonia.org

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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