

# SEEN AND HERD

We are stronger together, lets dazzle!

Issue 1  
March 2019



## Hello and Welcome fellow Zebras!

Tēnā koutou and welcome to the first of our quarterly newsletters.

We have been working hard behind the scenes in the last 12 months to set up the Ehlers-Danlos Society New Zealand (EDSNZ), our website, and becoming a registered charity.

Our main goal now is to get awareness and education out there so that we can support New Zealand individuals and families with EDS, and assist with any research in the international EDS/HSD community.

We have an amazing team so far, and we hope to share their stories with you all in the future.

EDSNZ has been set up for the EDS community and run by the those with EDS. If you feel like you can help us in anyway, whether that be with connections and networks you might have, a skill you can offer, or you would like to help fundraise, please get in touch.

May is Ehlers-Danlos Syndrome awareness month, and there are some ways that you can get involved further in this newsletter. The more we can get the conversation out there, the more we can educate others, so I'm excited to see how you all can help start this conversation.

We have made a connection with the Entertainment Book, and are offering this for sale nationwide (further details in this newsletter). If you would like to advertise this book on behalf of EDSNZ, please contact us, and we can arrange to send you flyers to hand out in your community.

We also extend our condolences to those feeling the effects from the tragic events that took place in Christchurch. Kia kaha ngā hoa ma, me ngā whānau. Arohanui ki ā koutou katoa i te pōuri nei. (Stay strong our friends and family. Lots of love to you all in this darkness).

We are excited that we have come this far and now want to help you educate others about the EDS journey.



Sending you all strength as we travel this EDS life together.

Ka kite anō, *Kelly McQuinlan*

### Want to volunteer?

We are a diverse group of individuals, and as such we all have different skills.

If you think you could help us out, feel free to message us on [contact@ehlers-danlos.org.nz](mailto:contact@ehlers-danlos.org.nz)



Ehlers-Danlos Society  
New Zealand

## Our New Logo!

We are very lucky to have a bunch of extremely talented individuals in our herd.

Joanne Robinson has been busy behind the scenes helping us with our graphic design requirements, including our awesome new 'Ziwi' Mascot!



EDSNZ is now an official Affiliate with the International Ehlers-Danlos Society.

Lara Bloom the International Executive Director has advised the best way that we can help the international movement is to get as many people as we can to sign up to the [global registry](#).

For those of us who have hEDS, they will be reaching out to 1000 individuals worldwide to help research and identify what gene variant might related to hEDS. They will be selecting these individuals from the Global Registry, so join us and show your zebra pride! It will help the international ongoing research.

We have a link for this on our website and our Society page. Or follow this link: <https://www.ehlers-danlos.com/eds-global-registry/>

## May Awareness Month

Ehlers-Danlos Awareness Month is fast approaching, and we would love for you to share your Ehlers-Danlos stories.

May Awareness Month is a great way to get creative, and increase awareness of Ehlers-Danlos Syndrome in your community. It might be something as simple as a bake sale, selling crafts, or setting up an information booth at a local farmers' market.

A great way to get friends, family, and co-workers involved is to encourage them to buy an Entertainment book through our website, or link them to the donation page on the EDS NZ website.

We also encourage you to write about your EDS journey, and share it with your local newspaper. Many community based papers welcome compelling personal stories from their readers. In May 2018 Lisa Preston had her EDS story published in the free weekend paper in the Eastern Bay of Plenty. Reading about Lisa's personal journey helped someone recognise that their symptoms might be related to Ehlers-Danlos Syndrome and they were officially diagnosed soon after! The more education we can communicate in our own neighbourhood, the more we can help others who are struggling to find answers.

If you are holding any events, or fundraising on behalf of Ehlers-Danlos Society New Zealand (using our name and/or logo), we require a short, online Event Registration Form to be completed on the EDS NZ website. By doing so, we can also help you advertise. Please feel free to share images of your event or local news stories with us so that we can publish them in our newsletters, on our website, or Facebook if you wish.

Thank you for helping to make Ehlers-Danlos Awareness Month 2019 the best ever!

## What's Happening in New Zealand

### Exciting EDS sabbatical for Bay of Plenty radiologist

Dr Matthew Preston is a radiologist with a special interest in EDS/HSD and a husband of someone with hEDS. He will participate in a four-week learning sabbatical during April and May 2019 at the Good Hope Ehlers-Danlos Clinic in Toronto, Canada, and the Royal National Orthopaedic Hospital in Stanmore, London, United Kingdom.

Matthew is already the Bay of Plenty's go-to person for health professionals who need help diagnosing Ehlers-Danlos Syndrome or managing symptoms in their EDS patients. He has presented many talks on EDS/HSD to health professionals in the Bay of Plenty/Lakes/Waikato area, substantially raising the awareness of the condition in his local community.

Matthew has also trained in prolotherapy in the United States, with specialised training in Ehlers-Danlos Syndrome under Dr Fraser Burling, a leading expert in EDS in New Zealand. When asked about his upcoming sabbatical, he stated, 'I'm very excited to have been accepted at these two world-class EDS clinics to learn more about the diagnosis and treatment of EDS/HSD. It will also be extremely valuable to study how they have set up and run their public health system EDS clinics so we can learn what might work in New Zealand.'

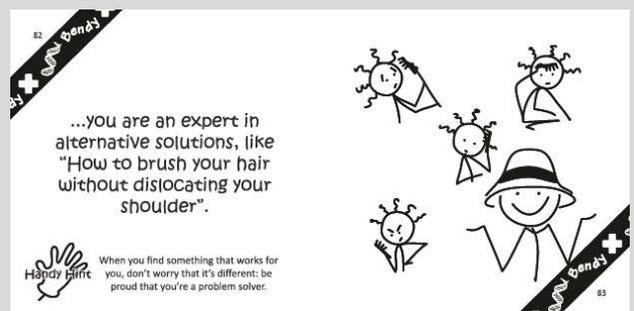
Please visit Matthew's website for more information: [www.matpre.nz](http://www.matpre.nz)

## We are Fundraising with Entertainment Book!

Your support really helps our fundraising, so we're thrilled to let you know about special bonus Early Bird Entertainment Membership Offers for loyal supporters.

Pre-order the NEW 2019 | 2020 Entertainment Membership and receive bonus offers you can use right away!

We receive 20% from all orders, so go to <https://www.entbook.co.nz/9r55878> for further details today!



## Patient Stories – Lisa Preston



It took 44 years to finally receive the correct diagnosis of Hypermobile Ehlers-Danlos Syndrome (hEDS).

My mother was a registered nurse and she knew the month I was born that something wasn't right. It wasn't normal for an infant on 100% breast milk to be severely chronically constipated, for both ankles to be folded over to the left in a very unnatural position, and to be able to bend my tiny fingers and toes in unbelievable ways. Doctors didn't have any answers.

As a toddler, I would refuse to continue walking. Doctors said I was throwing a temper tantrum but my mother knew I was in pain. She continued to seek answers from doctor after doctor throughout my childhood. I was extremely flexible so I excelled in all types of dance when the pain wasn't too bad. Still undiagnosed, orthopaedic surgeons wanted to fuse my over-flexible ankles at age 12, but thank goodness they decided against it after a third opinion. At age 13 and 14 I had 'snapping hip syndrome' in both hips and had surgeries to correct them. I also bruised easily, often felt like I couldn't hold up my own neck/head, had chronic severe allergy and gastrointestinal issues, and became faint with a racing heart when I stood up - but again, doctors didn't put it all together.

At age 14, pain also started affecting my upper body. This led to a misdiagnosis of Juvenile Rheumatoid Arthritis, an incorrect label that stuck with me for 30 years, even though I never showed some of the hallmark symptoms of Rheumatoid Arthritis, such as severe joint inflammation and joint damage. I missed an entire year of high school due to my pain levels and my inability to sit in a classroom all day. I learnt to manage my pain and fatigue better as an adult and managed to earn my Bachelors and Masters degrees, worked full time, and had three children.

Skipping ahead to age 33, I was diagnosed with a heart arrhythmia called Premature Atrial Contractions and

Tachycardia after I was hospitalised due to blacking out while driving in morning rush-hour highway traffic. Again, the doctors didn't put the pieces together. There were many times where I could tell from the doctors' words and body language that they thought I was being overly dramatic, or that the symptoms were in my head. I was grateful when things like the arrhythmia could be proven by tests.

At age 41 I got remarried and moved from Alabama in the United States to Whakatane, New Zealand. Additional symptoms started to appear, including Raynaud's Syndrome, nausea, headaches and diarrhoea. I saw a rheumatologist in New Zealand regularly but when the painful knuckles on my left hand turned black (which we now know was severe bruising), and an MRI showed no joint inflammation or erosions, the rheumatologist sent me for a second opinion in Rotorua. I will be forever grateful to Dr John Petrie for diagnosing me with Ehlers-Danlos Syndrome. As soon as I got home and Googled it, I couldn't believe that the answer we had been looking for over so many years was right there in one list. I ticked all the boxes. Finally, I 'fit' a condition that explained ALL of my seemingly-unrelated symptoms. I felt not only relief at finding answers, but also anger that it took so long to get them, and grief about what it might hold for the future.

A visit to Dr Fraser Burling in Auckland confirmed the diagnosis, and he got me started on better management of many of my symptoms. Sclerosant prolotherapy has helped many of my joints stay in place better, and has reduced my pain enough, that during a 10th anniversary trip to Canada last year, I was able to do mountain walks as long as 8km!

Because my diagnosis took so long, I am passionate about helping others find the answers they need. I run an EDS support group in the Bay of Plenty, and I'm the Treasurer of Ehlers-Danlos Society NZ. My hope is that in the future the awareness of Ehlers-Danlos Syndromes will be so widespread that no one will have to wait 44 years for a diagnosis like I did.

### Up and Coming Events 2019

4<sup>th</sup> April (NZT)

[EDS International Webinar](#)

6-7<sup>th</sup> April

[Madrid Global Learning Conference](#)

18<sup>th</sup> April (NZT)

[EDS International Webinar](#)

May

[EDS Awareness Month](#)

30<sup>th</sup> July – 1<sup>st</sup> August

[Nashville Global Learning Conference](#)

18-19<sup>th</sup> November

[Health Professionals – Scientific Meeting of the Rarer Types, Tokyo, Japan](#)

*Would you like to share your story with our herd?*

Get in touch today! [contact@ehlersdanlos.org.nz](mailto:contact@ehlersdanlos.org.nz)

### Contributors

- Kelly McQuinlan – President EDSNZ
- Lisa Preston – Treasurer EDSNZ
- Steph Aston – Secretary EDSNZ
- Dr. Matthew Preston
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**D** is for **dislocation**. Dislocations and partial dislocations (subluxations) are a key feature of EDS because the ligaments and tendons are stretchier and less stable. Both are extremely painful.



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