



**Performance Report for  
Ehlers-Danlos Society New Zealand  
Incorporated**

**Also known as  
Ehlers-Danlos Syndromes New Zealand**

**Year ending 31 March 2023**

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# Entity Information

## Who we are? Why do we exist?

Legal name of entity : **Ehlers-Danlos Society New Zealand Incorporated**

Also known as : **Ehlers-Danlos Syndromes New Zealand**

Type of Entity and legal basis (if any) : **Non-Profit Charitable Society**

Registration number : **CC55826**

Society number : **2704932**

### Entity's purpose or mission:

Our mission is to improve the wellbeing of those with Ehlers-Danlos Syndromes/Hypermobility Spectrum Disorders in Aotearoa New Zealand by raising awareness, improving knowledge by health professionals and providing support to patients.

Ensuring that medical professionals and patients have access to the correct information, and that patients are able to access support, and that patients know their rights and know how to advocate for themselves.

### Entity Structure:

Ehlers-Danlos Syndromes New Zealand's Leadership consists of the President, Secretary and the Treasurer. Our Committee size has fluctuated during this year. We had a total of 6 committee members at 31 March 2023.

### The main Sources of the entity's cash and resources:

This year we have received donations from fundraisers, personal donations, and as corporate donations, all of whom have been thanked for their donations. We have also done a merchandise-run of Hoodies and items from our website.

We have also connected with Techsoup to tap into their non-profit resources, have a non profit discount with Xero, and have connected with Reward Hub for a passive way of earning income on top of people's shopping.

### The main methods used by the entity to raise funds:

The main way we actively received money through our own efforts was through merchandise sales and May Awareness events.

*"We are continuing on with our mission and dealing with this new post covid environment. As people return back to a sense of normal, the reality is that the environment has changed. Advocating our needs has been more important than ever to ensure consumers aren't continuing to be lost in a new community of long-covid consumers. EDSNZ will continue to push in as many directions as we can to be heard."*

**-Kelly McQuinlan**



# Contact Details:

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Website:

[www.ehlers-danlos.org.nz](http://www.ehlers-danlos.org.nz)

Facebook:

[www.facebook.com/  
EDSNewZealand](https://www.facebook.com/EDSNewZealand)

Support Group:

[www.facebook.com/groups/  
looselyspeakingnz](https://www.facebook.com/groups/looselyspeakingnz)

Instagram:

[https://www.instagram.com/  
ehlersdanlossyndromesnz/](https://www.instagram.com/ehlersdanlossyndromesnz/)



## The Entity's reliance on volunteers or donated goods:

As at 31 March 2023 we currently have 6 Committee Members, two admins on the Support page. Some of these jobs are also performed by the Committee Members, all of whom are volunteers. We have donated more than 520 hours of volunteer hours during this year.

## Connectedness:

- Responded to 78 emails through [contact@ehlers-danlos.org.nz](mailto:contact@ehlers-danlos.org.nz).
- More than 1783 posts on Facebook during this time period with 1908 members, with up to 945 active members per day.
- We had a series of Hypermobility 101 sessions with Dr Leslie Russek. Each session we had between 20-30 people in attendance. Since then we have had 723 Page views on this section of our website.
- 10,767 new website visitors and 14,558 sessions, from 90 countries. Our top 3 countries: 71.81% from New Zealand, 14.59% from USA, 5.15% from Australia. An increase from 4050 users in 2022.
- 948 likes on our Society Facebook page, 291 new likes since 2022.
- 334 visits on Instagram account.
- 393 members joined as members of our society.

## Awareness & Knowledge:

- We have established a clinical advisory panel (CAP), a group of clinicians to help increase knowledge and awareness in New Zealand
- We have established a newly diagnosed seminar to help support people at the beginning of their journey.
- We ran a survey for our communities needs, wants and issues currently.
- Wrote 7 letters to 100 government figures and gained support from Minister Chris Hipkins, and response from Rt Hon Prime minister Jacinda Adern, Hon Minister Andrew Little, Hon James Shaw, and Hon Eugenie Sage
- Had Dr Leslie Russek do a series of education for our community over 10 weeks
- Our community, along with ourselves, were able to provide 7 stories in the media
- Submitted on the precision health proposal
- Submitted on the Woman's Health Strategy
- Submitted on the Health of Disabled People Strategy
- EDS had a massive representation and return lots of data in RDNZ's white paper survey results which has been continued to work along side RDNZ's advocacy efforts
- RDNZ did a series of videos, including Vashti's EDS journey which have continued through from 2021.





## Representation

During this financial year, we have been able to voice our collective thoughts at the following meetings/huis/frameworks/working groups:

- Submission for Long-Term precision health
- Submission on Womans Health Strategy
- Submission on Health of Disabled People Strategy
- Paula Tesoriero and the new Ministry Whaikaha
- Consumer Health Forum Aotearoa Hui
- Talking with Mental Health Wellbeing Commission
- EDS Echo Summit Series
- 3 Committee members on EDS Echo Community Leaders and Educators sessions.
- Mind & Body Seminar
- Peer Paradigm Virtual Seminar
- Talking with Taikura Trust to get a better understanding of NASC systems
- Helping create a Rare Disorders Hui
- Disability Advisory Panel Community Engagement Forum
- Whāriki Huihuinga/ Allyship: partnering for equality
- Long Term Conditions virtual forum
- See Us online Forum
- Whāriki Hui | Groundwork: Facilitating change
- HQSC Consumer Hui

Relationships with:

- Paula Tesoriero
- Rare Disorders NZ
- Carers Alliance
- The Ehlers Danlos Society (International) & Ehlers Danlos Aust
- Te Pou
- ACC
- Shiloh
- HQSC
- Stuff.co.nz

Awareness in media

- <https://www.newshub.co.nz/home/lifestyle/2022/12/ehlers-danlos-syndrome-the-bendy-body-disease-affecting-millions-across-the-globe-how-to-test-for-it.html>
- <https://www.stuff.co.nz/national/health/coronavirus/127801934/covid19-woman-denied-vaccine-exemption-despite-rare-condition-and-reaction>
- <https://www.stuff.co.nz/national/129749564/accessibility-nightmare-goes-from-bad-to-worse-for-woman-after-floods>
- <https://www.stuff.co.nz/national/health/300649884/finding-hope-bright-future-after-lifechanging-surgery-in-germany>
- <https://www.stuff.co.nz/national/129528835/young-dad-with-rare-condition-dies-five-weeks-after-birth-of-daughter>
- <https://www.stuff.co.nz/national/health/130203286/woman-in-chronic-pain-has-to-raise-90k-for-jaw-surgery--if-she-lived-in-auckland-it-would-be-free>
- <https://www.stuff.co.nz/life-style/homed/garden/300759200/i-was-housebound-and-could-hardly-walk-gardening-saved-me-says-22yearold-florist>



## Statement of Receipts and Payments Financial Report

	This Year \$		Last Year \$
<b>Operating Receipts</b>			
Donations	341		335
Personal Fundraising	20		125
Corporate Donations	183.99		150
Company Fundraising	161.55		209.87
Event Fundraising	4,777.26		2,164.11
Merchandise sales	1,043.60		1931.69
Postage from sales	130		241.19
Fees, subscriptions and other receipts from members	0		0
Rounding	0		0.08
Interest, dividends and other investment income receipts	38.21		0.86
Other operating receipts	0		13.32
<b>Total Operating Receipts</b>	<b>6,695.61</b>		<b>4,929.93</b>
<b>Operating Payments</b>			
Payments related to public fundraising			0
Payments/fees relating to events	-651.86		-180.76
Payments related to merchandise	-990.44		-1,164.13
Postage from merchandise	-51		-26
Merchandise Refunds	-437.6	NEW	
Professional Development Expenses	-193		-392.58
Volunteer and employee-related payments/discounts	0		0
Postage reimbursement	-135.55		-200.57
Patient Support Expenses	-56.9		-2,677.68
Patient Support Expenses Outstanding/Paid	-500		-500
Public Awareness and PR (website transfer and new layout)	-287.76		-542.85
Grants and donations paid	0		0
Incurring Fees and Services	-664.74		638.33
Other operating payments	-151.84		0
Outstanding Invoices End Of Year	470.93	NEW	
<b>Total Operating Payments</b>	<b>-3649.76</b>		<b>-5,322.90</b>
<b>Operating Surplus or (Deficit)</b>	<b>3045.85</b>		<b>-392.97</b>
<b>Capital Receipts</b>			
Receipts from the sale of resources	0		0
Receipts from borrowings	0		0
Bank accounts and cash at the beginning of the financial year	434.17		827.22
<b>Increase/(Decrease) in Bank Accounts and Cash</b>	<b>3045.85</b>		<b>-402</b>
<b>Bank Accounts and Cash at the End of the Financial Year</b>	<b>3480.02</b>		<b>434.17</b>
<b>Represented by Cheque Account</b>	<b>3480.02</b>		<b>425.22</b>
<b>Represented by Stripe Account</b>	<b>0</b>		<b>0</b>
<b>Represented by PayPal Account</b>	<b>0</b>		<b>8.95</b>
<b>Total Bank Accounts and Cash at the End of the Financial Year</b>	<b>3480.02</b>		<b>434.17</b>



## Comment on financials

We saw a definite decline in sales during the 2022 financial year period. This was due to some unforeseen circumstances that were beyond our control - one of our suppliers closed, which lost us some of our most popular merchandise (Reusable Zebra cups). We had issues with our second Hoody order which had been very popular the year before - poor communication from the supplier with stock being delivered a lot later than expected due to errors on the suppliers end, combined with a noticeable increase in cost and decrease in quality led EDSNZ to offer a refund to all customers who had pre-ordered a hoody as we couldn't in good conscious charge our customers so much for poor service - this one order set us back nearly \$500 in sales which would've had us nearly on par with 2021's sales.

On the plus side we saw a definite increase in donations from various sources which more than made up for the loss in merchandise sales. We were involved with the book launch of Nicole Martin's book "Stay Sane With Chronic Pain". While this book was offered for free as per Nicole's wishes, we did see a rise in donations through our shop as people were very quick to add a \$2 or \$5 donation to their order. We have had over 100 downloads of Nicole Martin's book.

For May Awareness Month we did our Distance Challenge, and this year we also launched our first online Read-A-Thon for our less mobile community members. Our Distance Challenge participants numbered less than 2021's, but increased money raised on the year before by nearly double with \$3900 (before removal of costs) raised. We had 3 participants in our Read-A-Thon and they raised \$699 (before removal of costs). We were grateful to be able to bring outside sponsorship on board this year who gave us products for free that we could give away as prizes to our participants. We once again used Raisely as our platform for hosting these May Awareness Month events. Our costs for running both fundraisers was \$651.86 between Raisely's fees, Paypal's fees and postage costs for sending out prizes to our participants.

In December we had a member of our community launch their own fundraiser through our "Create A Fundraiser" Raisely website, they raised \$20 on our behalf. We launched a merchandise fundraising campaign through Fundraise Factory who ran the campaign on our behalf which included advertising, selling and shipping the stock on our behalf. While this wasn't a complete success like we had hoped, we had some sales, and we will be looking at utilising them again going forward due to the high quality of goods they supply.

We paid off the final of the invoice for the Te Reo Māori translations this year with funds from our May Awareness Month fundraising.

As always, we are incredibly grateful to our community for all their support with merchandise sales and fundraising on our behalf so we can continue our mission to raise awareness and provide accurate information and support for free to the whole community. Our aim for the next year is to see how we can further push the fundraising tools we have utilised so far to benefit the community further.



# Notes to our Performance Report

## President's note

The health environment has changed since covid, and as such we are finding that consumers are needing to advocate harder to be heard. We are also needing to understand more steps that are needing to be taken to even attend appointments, and doctors, nationwide, have been harder to see as we see the flu and colds come back with a punch.

We were able to run a survey this year, which is a great way for us to hear from our community about their struggles, their wants, and ideas, which is an invaluable source of information as we continue on our mission.

Our committee has been feeling the effects of the last couple of years and have been taking more time to focus on mental health as a result.

Our secretary and mental health link continues to be a valuable point of contact for all mental health related questions, and was able to run a mental health strategy session for the team and hub leaders, to ensure they have an understanding of steps that are needed to be taken in a point of crisis for members.

Our committee member, Wendy, has set up the Hypermobility 101 sessions with Dr Leslie Russek, which have been extremely valuable and is now a great resource for our community.

We are seeing changes on the horizon, with the new ministry of disabled people, Whaikaha, and an overhaul of current medical systems and services, which we have been able to feed our communities thoughts to.

Our new Clinical Advisory Panel (CAP) was created to help share information and start to create a network of knowledgeable professionals that can help support each other's work and in turn the consumers. The goal behind this group is to get professionals from all areas of work, and that other professionals can contact for help and support; This will help with their workloads, and also help support clinicians and consumers who may be unable to access these professionals directly.

Our lead clinician of CAP, Jacquelyn Shirmer, had noted how helpful a 'newly diagnosed' like seminar could help our community (after seeing this in another health community) and together with the CAP team, we created a newly diagnosed seminar for our community. We provide information that they may be asking themselves at the beginning of their journey. We also have a Q&A session at the end when we ensure to have more than one 'specialist' there to help answer any general questions they may be having.

We continue to welcome any community feedback, thoughts, and ideas to continue to help us with our mission.

I would also like to acknowledge the struggles of people within our community. No two people with EDS/HSD have the same journey. The impact of one's journey impacts not only the individual but friends and whānau, work and education journeys.





## This Performance report has been approved by the:

EDSNZ President, Treasurer and Committee  
for and on behalf of Ehlers-Danlos Society New Zealand Incorporated

Date \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_ Signature \_\_\_\_\_

Name Kelly McQuinlan  
President

Name Tara Apperley  
Treasurer

*Refer to next page for scanned  
signatures*

