

### Our Vision

Be the trusted source of information, education and support for those impacted by endometriosis in Aotearoa.



### Our Purpose

Improve lives of those with endometriosis

### Our Values



#### Caring

We deeply understand the challenges our community face on their unique journeys with endometriosis. We tautoko people and whānau to find a way forward with hope and strength.



#### Committed

We collaborate with and respond to our endometriosis community to provide relevant information, education and support that meets people where they are at on their journey.



#### Connected

We are dedicated to growing, learning, and advancing as an organisation so that we can improve and sustain positive health outcomes for future generations.

Finding a way forward with hope and strength.

ENDOMETRIOSIS  
NEW ZEALAND  
SUPPORTERS | 2021 - 2022

### Thanks to our generous supporters

- Aotearoa Gaming Trust
- Riccarton Rotary Youth Trust
- New Zealand Lottery Grants Board
- The Lion Foundation
- Rātā Foundation
- Pub Charity
- Mainland Foundation
- Royston Health Trust
- Auckland Airport Community Trust
- Kiwi Gaming Foundation
- Community Trust - Mid and South Canterbury
- Ministry for Women- Covid 19 Community Fund
- Air Rescue and Community Services
- The Jones Foundation
- Adelphi Insurance

## ANNUAL REPORT

# Endometriosis New Zealand

2021 - 2022



endometriosis  
new zealand

Endometriosis  
New Zealand

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## ENDOMETRIOSIS NEW ZEALAND

### Strategic Pillars

2022 - 2027

#### Leadership

Lead positive change to those living with or impacted by endometriosis.



#### Impact

Collaborate with all communities to increase the impact of our mahi.



#### People

Strengthen our people, capability and relationships.



#### Systems and Processes

Develop sustainable, fit-for-purpose systems and processes.



#### Brand

Be recognised as the trusted, national organisation for the endometriosis community.



#### Funding

Develop financial stability as a not-for-profit organisation to enable change for future generations.



## ENDOMETRIOSIS NEW ZEALAND

### Awareness Month

2022

Endometriosis Awareness Month, March 2022 produced record breaking community engagement, general public awareness, corporate support and endometriosis education.

We provided many opportunities for our community to support us during the month, by creating Endo Challenges, High Teas and our Online Auction.

20 members of the endometriosis community took on an 'Endo Challenge' where they created a physical challenge to complete throughout the month. We were thrilled to raise over \$24,000 thanks to an incredible 394 individual donors across these challenges.

10 individuals hosted an in person High Tea, despite the challenges presented by Covid-19, to support ENZ and spread endometriosis awareness. 110 people bid in the ENZ Online Auction that was supported by over 40 generous businesses.

12 corporate sponsors partnered with Endometriosis New Zealand during awareness month, including Go Media, who kindly sponsored a nationwide billboard campaign in 40 prominent sites across the country, so that we could share our messages and raise awareness across New Zealand. Tronque, another sponsor, generously provided their products for a giveaway to the community on International Women's Day.

Across the media and on social media, endometriosis awareness increased significantly and over \$50,000 was raised by our endometriosis community.



Thank you again to all those involved in this year's Endometriosis Awareness Month.

## ENDOMETRIOSIS NEW ZEALAND

### Maddison's Endo Story

*My name is Maddison I am 25 years old. I was born in Christchurch, New Zealand.*



#### SYMPTOMS

My symptoms began from the beginning of menstruation when I was 14. I was unable to get out of bed for the first 2-3 days of each cycle in agony.

I went to the doctor numerous times throughout the years, but endometriosis was never discussed. They said I might have PCOS, then IBS, then that I probably had Crohns or Ulcerative Colitis, none of which ended up being a concrete diagnosis and always fell through with further testing.

#### PHYSICAL IMPACT

I feel that I have had no quality of life for 8 years living with endometriosis. From the beginning of menstruation I had extremely heavy periods and cramping so painful that I would keel over into a ball on the ground.

#### MENTAL IMPACT

The biggest battle I have faced from endometriosis, is that of my mental health. I feel a lack of self-worth and I wake up every day questioning why I deserve this pain and wondering if it will ever stop.

#### IMPACT ON RELATIONSHIPS

When I was younger, it was really hard on my family having to always take me to doctor's appointments and to hospital in the middle of the night, only to always be told the same thing - there's nothing wrong with her - it's just growing pains - it's just in her head, she will grow out of it.

#### PROFESSIONAL IMPACT

It's always been really hard having to take so much sick leave. It was hard to explain to employers why I was having all this time off without saying "sorry I just have a sore stomach."

#### DIAGNOSIS

I was officially diagnosed with endometriosis via my third laparoscopy surgery on the 21st of February 2022 after 7 years of pain and debilitating health issues. The road to my diagnosis was definitely a long, bumpy one. I had two exploratory lap surgeries, two colonoscopies, one gastroscopy, one camera endoscopy and countless stays in hospital.

#### HOW ENZ HELPED

Periods shouldn't stop you from living your life. Endometriosis New Zealand has helped me to know I am not alone, and that unfortunately there are others out there just like me.

## Research

Endometriosis New Zealand partnered with the Medical Research Institute of New Zealand (MRINZ), Gynaecology Group and RePromed, Canterbury District Health Board, University of Otago, University of Auckland, Te Herenga Waka – Victoria University of Wellington, Oxford Women’s Health at Forté Health, and Western Sydney University’s NICM Health Research Institute and Translational Health Research Institute to develop the study ‘An Aotearoa New Zealand survey of the impact and diagnostic delay of endometriosis and chronic pelvic pain’.

The study consisted of 800 women and those assigned female at birth with chronic pelvic pain and endometriosis. Study findings revealed the profound impact endometriosis and chronic pain are having on New Zealanders – including their education, career, sex life, whānau relationships and mental health.

Key study findings show that this is a serious health issue deeply affecting the quality of life for so many, there is significant diagnostic delay, and demonstrates an urgent need for the health system and society to respond.

### KEY FINDINGS



67% of respondents said their pelvic pain symptoms caused significant problems with their partner.



81% of respondents avoided sex because of chronic pelvic pain.



32% of respondents said their pelvic pain symptoms prevented them from attending work and carrying out basic life tasks in the last 3 months.



73% of respondents were scared to tell their employer about their pelvic pain because of fear it might affect their prospects.

Participant responses showed that it took an average of five doctor visits, before formal endometriosis diagnosis.

The study analysed the types of pelvic pain symptoms individuals faced, as well as the severity of these symptoms. 83.6% of respondents experienced pelvic pain with their period, 10.5% often felt pelvic pain and 5.8% occasionally felt pelvic pain. Severe period pain was the most common pelvic pain symptom, with other symptoms including non-cyclical pelvic pain, ovulation pain, chronic fatigue, subfertility, deep dyspareunia and cyclical symptoms.

Overall, study findings showed that a significant negative impact was demonstrated in all domains of respondents lives.

Endometriosis New Zealand is committed to continue being the voice for endometriosis and chronic pelvic pain sufferers in New Zealand. The creation and publication of this study shows that investment in this research is pivotal for our community and ensuring they get the support they need to best manage their health and ensure greater quality of life.

## ENDOMETRIOSIS NEW ZEALAND

### Impact

“The support of the social media group, even though I’m shy - has improved my quality of life in a significant way. I’m no longer alone.”

“Women’s health is still a taboo subject and anyone who does not suffer from Endo really does not understand. To realise that you are not on your own in this journey through the Endo page and group as a whole has made a huge positive impact on my life. Thank you.”

“Abby was very kind to me and took the time to listen, support and take my feelings into consideration. It was nice to know that she was there to hear me out and that I wasn’t going crazy after years of not being heard.”

“I’m just so grateful as a newly diagnosed endometriosis patient that this service is available and I really believe the advice I received from Abby will go a long way in helping me to live a normal life.”

“The Facebook group has a supportive vibe and it reminds you that you are not alone in your struggle.”

### Feedback received from our support services

“I was finally taken seriously and advised there is a way to be diagnosed. I finally felt supported and not brushed off and told to deal with the pain, that it is normal. Thank you, I am glad I found you and was able to talk to you as well”

“She was awesome. She helped me feel empowered and gave me important information so that when I speak to my GP I know what I am talking about. She made me feel heard and also from her own experiences made me feel not alone in this.”



## ENDOMETRIOSIS NEW ZEALAND

### Facts



**120,000**

girls, women and those assigned female at birth live with endometriosis in Aotearoa.

**1 in 10**

girls, women and those assigned female at birth live with endometriosis in Aotearoa.

ENZ Membership of nearly **6,000** members.

Private Online Social Media Group of nearly **4,000** members.

Private Endo Help Phone Appointments

**260+** appointments per year

Over **4,500** endometriosis information resources provided to the community annually, free of charge.

Website **60,000** visitors per year

Internationally there is an average delay of **8** years in receiving a diagnosis.

On average endometriosis sufferers required **5** doctor visits before receiving a diagnosis.

**10** research collaborations with different organisations to promote and disseminate endometriosis research.

ENZ has supported people living with endometriosis and their whānau for almost **30** years.



## ENDOMETRIOSIS NEW ZEALAND

### Year in Summary - CEO

2021 was a milestone year for Endometriosis New Zealand (ENZ), with a range of future-thinking initiatives implemented to ensure we can improve the lives of those with endometriosis across Aotearoa long-term.

Board Chair, Felicity Evans and I are immensely proud of the transformation led by our team, and we are excited to highlight the important work completed in the last financial year, as well as the developments that are to come.

First, we must offer a huge thank you to ENZ co-founder Deborah Bush, who departed the organisation after more than 35 years positioning ENZ at the forefront of internationally recognised endometriosis services. Deborah’s dedication to providing knowledge, innovative programmes and support networks for those with endometriosis has benefited tens of thousands of people all over New Zealand, and her expertise, leadership and vision will be sorely missed by the Board,” Felicity says.

We moved into our new national office in Addington, Christchurch. We have made the most of the opportunity to hold hui in-person and virtually in our new space, and it has proven to be a venue where we can connect with our community and continue to evolve our important work.

Four new members were appointed to the ENZ Board: Dr Michael Wynn-Williams, Dr Nicola Ngawati, Sandra Matthews, and our Board Chair Felicity. These new members bring diverse strengths as leaders in their communities, as well as their commitment to improving outcomes for people living with endometriosis.

Felicity is a longstanding advocate for women and diverse communities across Aotearoa. She is an experienced director and organisational change specialist, with global experience leading transformation.

Dr Michael Wynn-Williams is an Auckland-based Gynaecologist and Endometriosis Specialist that leads the Minimally Invasive Surgery Team at Te Whatu Ora Te Toka Tumai Auckland. Michael has more than 19 years’ experience caring for people with endometriosis.

Dr Nicola Ngawati (Ngāpuhi, Ngāti Hine) brings her extensive experience in diversity and inclusion to the Board. She also serves as a Board member of Tāwhiri Limited, as a Ministerial appointment to the Board of Diversity Works New Zealand, and

was the inaugural Crown representative on the WAI 2700 Mana Wāhine Kaupapa Inquiry Joint Research Committee.

“Sandra Matthews has extensive experience in the charitable and volunteer industries. She has a financial background and brings strengths in communication, strategy development and change management.”

Board Member and Treasurer, Brylie Gray moved on from the organisation following three years of commitment and immense dedication to our important work.

The four new appointments joined our existing Board members Glenda Harding, Dr Fiona Connell and Katie Holcroft in overseeing our strategic direction and got straight to work on developing a new strategic plan to ensure our vision and purpose align with our priorities moving forward.

Our renewed vision is to be the trusted source of information, education and support for those impacted by endometriosis in Aotearoa. Our strategic pillars will provide focus to our work going forward, driven by what we want our organisation to achieve and how we plan to achieve it. These pillars are Leadership, Impact, People, Systems and Processes, Brand, and Funding.

Our community is our priority, and we will continue to support people at all stages of their endometriosis journeys in ways that will provide maximum impact. Engaging with stakeholders across all sectors to improve health outcomes is an essential aspect of how we will maintain traction in partnership with our ENZ community.

I look forward to seeing ENZ continue to evolve in line with our new strategic plan over the coming year. Seeing those living with endometriosis take control of their condition and feel heard is why we do the work that we do.

Thank you all for your ongoing support. I look forward to seeing the results of what we achieve together as a community over 2022 and beyond.

Naku noa nā, Tanya Cooke

TCCooke

CHIEF EXECUTIVE, ENDOMETRIOSIS NEW ZEALAND