Impact Report

April 2022 – October 2023

MIGRAINE FOUNDATION
Aotearoa New Zealand

Contents

1 Who We Are

MIGRAINE FOUNDATION AOTEAROA NEW ZEALAND

is an incorporated society and registered charity.

We're an inclusive, open, active and action-orientated organisation.

We value respectful partnerships and relationships and evidence-based information.

Supporting people with migraine is at the core of everything we do.

OUR PILLARS OF SERVICE

support

information

advocacy & awareness

research

leadership & sustainability

Our vision is to minimise the health, economic and social burden of migraine in Aotearoa New Zealand.

OUR MISSION

To raise awareness of the impact of migraine disease and support people living with migraine in Aotearoa New Zealand.

Why We're Here

Globally, migraine disease affects approximately 1 in 7 people and is one of the most disabling medical conditions. Migraine disease is estimated to affect 753,000 people in Aotearoa New Zealand, although more research is needed for a more accurate picture of the prevalence and impact of migraine in Aotearoa New Zealand.

Migraine disease is under-researched, under-funded and under-diagnosed. Treatments and knowledge about migraine have improved in recent years; sadly Aotearoa New Zealand has been left behind, with poor access to migraine specialists, newer migraine-specific treatments and basic migraine care.

Migraine Foundation Aotearoa New Zealand exists for all people in Aotearoa New Zealand living with migraine. We're dedicated to connecting people living with migraine, supporting positive change and ensuring our voice is heard.

Our foundation is voluntarily run by

3

co-founders who come from the healthcare and legal professions and all live with migraine.

We're the only migraine charity in New Zealand supporting the

753,000

people living with migraine disease in Aotearoa.

Our foundation is supported by a Clinical Advisory Group of

4

volunteer health professionals.

During this, our first

1.5

years of operation, we've been financially supported through donations and a grant.

2 Chairperson's Report*

Sarah Cahill, Chairperson and co-founder
Migraine Foundation Aotearoa New Zealand

I'm honoured to present the first Chairperson's Report for Migraine Foundation Aotearoa New Zealand.

Writing this report has been a great opportunity to reflect on what we've achieved since we first launched on 1 April 2022.

On that day, we started with a website, a bit of social media and a huge wish list of things we wanted to do. Since then, all of those have grown, and then some, especially our to-do list.

Our first big milestone was achieved on 22 July 2022, just a few short months after we launched, when we became a registered New Zealand charity.

This was our goal from the start, even though it comes with more accountability and a lot more paperwork.

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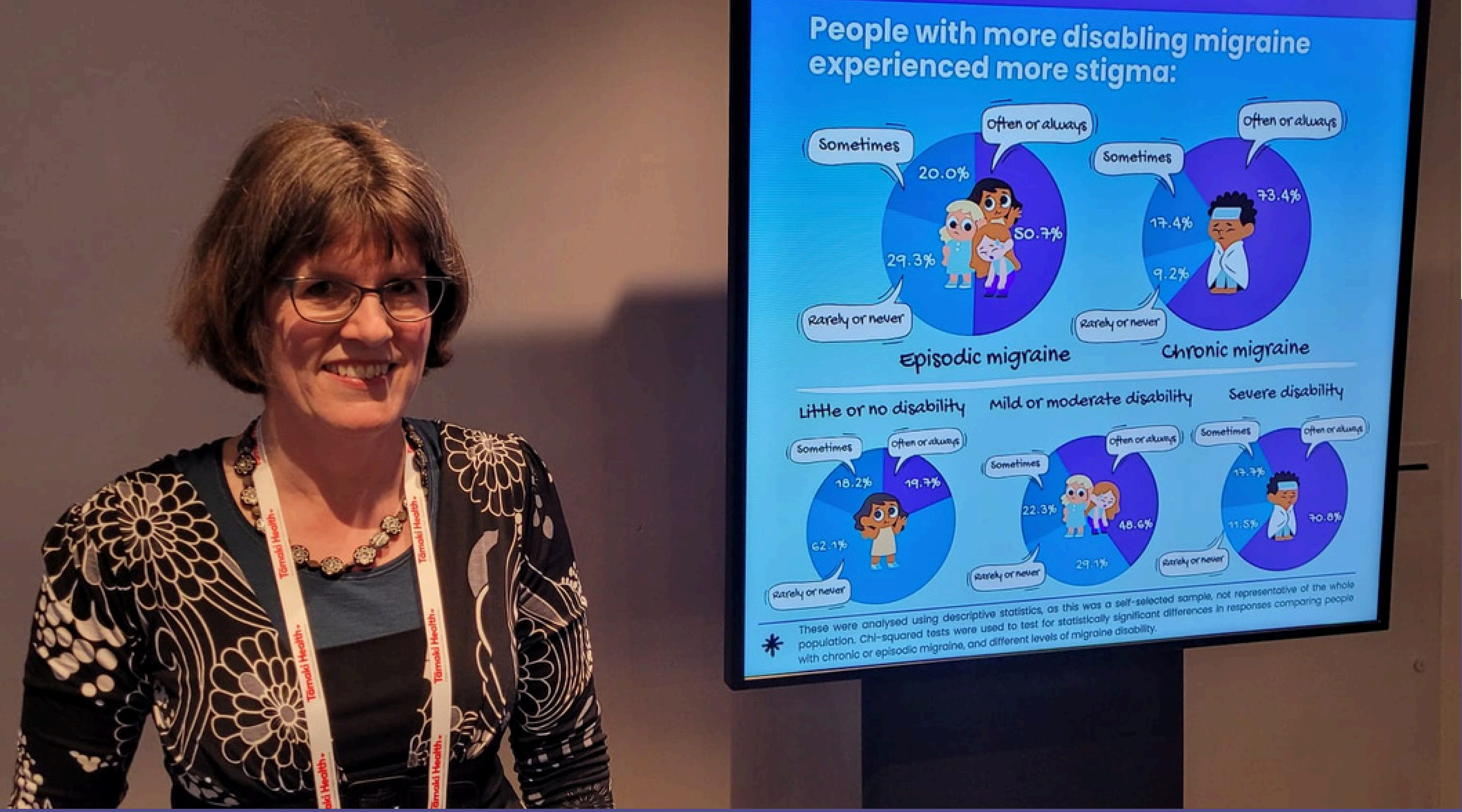
* As presented at the AGM on 25 October 2023.



Dr Fiona Imlach, Migraine Foundation co-founder, presented a poster of MiANZ Survey data at GP23, the Conference for General Practice hosted by the Royal New Zealand College of General Practitioners (July 2023)

Our biggest piece of work last year was our Migraine in Aotearoa New Zealand (MiANZ) survey. This was an online survey we ran from 22 August to 7 October 2022.

Even before we launched, we knew there was a lack of migraine research and data in New Zealand, and without data it's harder to prove to those making the health decisions just how prevalent and disabling migraine is.

We received 579 survey responses, and following removal of incomplete responses and those unlikely to have migraine, we had 530 responses for analysis. At the time, we'd been in operation less than 6 months, so we were thrilled to have so many people respond to our survey, which took about 20 minutes to complete.

We collected a lot of data about the lived experiences of people with migraine in New Zealand, including both qualitative and quantitative data.
We've published 23 key insights reports using the data, used the data in our submission to Pharmac to fund the new migraine medication Emgality, presented a poster at a GP conference, presented the data during health professional webinars and continue to disseminate the results in various ways.

A heartfelt thank you to Fiona for leading this piece of work. It's been a huge undertaking and there's still so much more work to do disseminating the results. Thank you also to Sue Garrett, a new volunteer to our team who has been helping Fiona with research publications.

Since we launched, we've been supported by a cohort of neurologists in New Zealand who specialise in migraine and headache disorders.

They've been a crucial sounding board, provided us with ideas and a clinical point of view, reviewed information and offered networking opportunities with other clinicians and organisations.

Their individual contributions have been invaluable in many ways – everything from strategic planning to networking to disseminating accurate information about migraine and its treatment.

In late 2022, we formalised this arrangement with the formation of the Migraine Foundation Aotearoa New Zealand Clinical Advisory Group.

The founding members of this group were neurologists Dr Rosamund Hill, Dr Desiree Fernandez and Dr Pyari Bose.

In early 2023, we welcomed Dr Paul Vroegop, a specialist pain medicine physician and child, adolescent and adult consultation-liaison psychiatrist to the group.

We continue to meet with the Clinical Advisory Group quarterly and keep in regular contact.

**Dr Rosamund Hill,
Neurologist**

**Dr Desiree Fernandez,
Neurologist**

**Dr Pyari (Ray) Bose,
Neurologist**

**Dr Paul Vroegop,
Specialist Pain
Medicine
Specialist &
Psychiatrist**

**Members of the Foundation's
Clinical Advisory Group in 2023**

Advocating for the funding of the new class of migraine medications, that target the neuropeptide calcitonin gene-related peptide (CGRP), has been another big piece of work over the past 12 months.

In November 2022 we submitted our application to Pharmac to fund galcanezumb (Emgality) for both episodic and chronic migraine.

We've had ongoing dialogue with Pharmac, both via email and in person meetings to discuss our application.

In August, we met with Pharmac in person to provide feedback and insight about the impact of migraine in New Zealand, and discussed the funding of both Aimovig (erenumab) and Emgality, which are injectable monoclonal antibodies targeting CGRP, plus atogepant, an oral anti-CGRP medication.

We presented Pharmac with a 100+ page book of people's stories of living with migraine and how anti-CGRP medications have made a huge difference to their quality of life. Thank you to Dr Rosamund Hill and Dr Desiree Fernandez who also attended the meeting.

Following this meeting, we were invited to attend Pharmac's Neurological Advisory Group meeting in September to give a 15 minute presentation about migraine and the impact.

We provided the group with an extended version of the patient stories book and it was good to be in the room with neurologists who were discussing CGRP medications. A huge thank you to our migraine community who shared their stories and to Migraine Foundation co-founder Suzanne Vale for hours of design work.

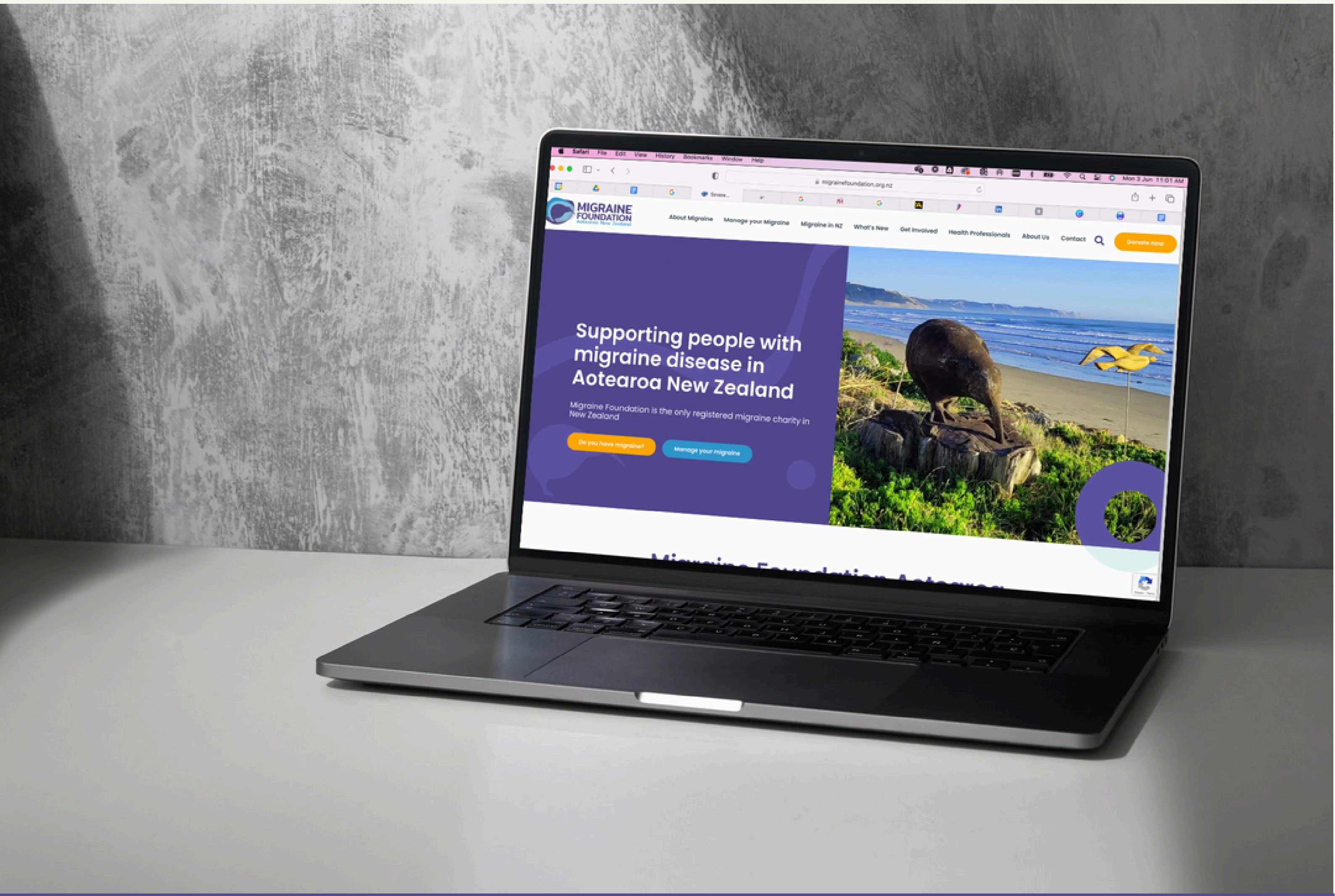
Co-founders Suzanne Vale and Fiona Imlach visiting Pharmac to present on the impact of migraine

Another success we're proud of is our advocacy efforts to get migraine questions included in the New Zealand Health Survey.

Migraine hasn't been asked about in New Zealand since 2013, and even then the questions were flawed, so we were thrilled when the Ministry of Health confirmed with us in June that some of the migraine questions we advocated for inclusion will be included in the 2023/24 survey. The data we get from this will add to the data we have from our survey.

In June, our grant application to the Lion Foundation to redevelop and expand our website was successful, and we received an $8,000 grant. We're working with a web design agency for this work and our new website should launch before Christmas.

Over the year, we've been fortunate to connect with other migraine and neurological groups. We've joined the New Zealand Neurological Alliance and we're members of the International Headache Society Global Patient Advocacy Coalition (IHS-GPAC).



Supporting people with migraine disease in Aotearoa New Zealand

Migraine Foundation is the only registered migraine charity in New Zealand

Our new website, made possible by a Lion Foundation grant, is due to launch Christmas 2023

There are so many other wins we've had over the year that I'll just mention briefly.

We've:

- published a number of press releases in the media
- published articles in health professional magazines
- developed patient and health professional resources
- submitted Official Information Act requests for information on the number of people with migraine on benefits, neurology referrals and Botox™ treatments for migraine
- held community meetups throughout New Zealand
- held our first migraine information evening in Auckland with Dr Rosamund Hill and Dr Paul Vroegop as guest speakers
- launched an advocacy toolkit
- provided feedback to the Ministry of Health on the Women's Health Strategy
- met with representatives from the Mental Health and Wellbeing Commission
- presented webinars
- kept our website up-to-date
- sent out monthly newsletters to our ever growing subscriber base
- launched a Migraine Foundation membership so people can support us financially
- answered hundreds of emails
- kept our social media channels going
- kept our private Facebook support group going
- met with pharmaceutical representatives and MPs
- supervised 4 undergraduate students from Auckland University School of Population Health.

I know I've missed some achievements but we have to keep moving!

5

press releases published raising awareness of migraine disease and reducing stigma

10

community in-person meetups of people with migraine disease held

1st

in-person event held with guest speakers, Dr Rosamund Hill and Dr Paul Vroegop

23

monthly newsletters sent to a growing number of subscribers

476

monthly newsletter subscribers

3

webinars presented:
My Health Hub
New Zealand Pain Society
NZ Pharmaceutical Society
(AKL branch)

888

Facebook online support group members

2

awareness campaigns

1st

online community meet-up held catering for people with migraine who struggle with going out

4

undergraduate students hosted

Our biggest challenge for the upcoming year is to secure funding to ensure our longevity and make sure we can continue to do the work we want to do.

We were unsuccessful in our application to NZ Lottery Grants Board | Te Puna Tahua for operational costs funding, but we remain positive that as we continue to make our impact more visible the financial support will grow. It's time- consuming applying for grants but it's something we know we have to continue to prioritise. For now, the three of us continue to volunteer our time to keep the charity running and rely on donations to cover some of our costs.

Thank you to you, our founding members, for supporting us from the start.

Thank you to our migraine community, our volunteers, our Clinical Advisory Group members and everyone else who has supported us this year.

Finally, I want to take the opportunity to thank Fiona and Suzanne. I don't think any of us realised the amount of work it would take to run a charity when we decided it was a good idea to start one, and I know personally I'm glad I didn't or else we may still just be talking about it.

I feel incredibly fortunate to be working alongside you both. I continue to be blown away by the commitment we all share to make Migraine Foundation Aotearoa New Zealand a success, and the hours we give every single week to keep the organisation growing and thriving.

Let's continue to celebrate the wins and know that our work is making a difference to the 642,000* people in New Zealand with migraine.

Sarah Cahill
Chairperson and co-founder

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* At the time of publishing, this figure had been revised upwards to 753,000 for the period covered by this report, as stated elsewhere in this report.

Our first migraine information evening was held in August 2023 in Auckland with Dr Rosamund Hill and Dr Paul Vroegop as guest speakers

Information & Awareness: Drawing the prize winners for our first Shades for Migraine competition in June 2022

WHAT IS THIS WONDER?

By Dr Jamie Mātenga Wood

By Kirilee Bell

A KIWI REFUGEE

THANKFULLY EVERYTHING CHANGED

By Caitlyn Kolumban

By Amanda Lo

MIGRAINE BY NUMBERS

Compiled by

MIGRAINE FOUNDATION Aotearoa New Zealand

New Zealanders' stories of MIGRAINE DISEASE & CGRP MEDICATIONS

By Fiona Iml

LIFE CHANGING

But it took tim

MFANZ presented a book of New Zealander's stories to Pharmac in August 2023

Migraine Foundation's first meeting with neurologist, Dr Rosamund Hill, who is one of a team of specialists donating their time to support MFANZ's work.
Left to right: Dr Fiona Imlach, Dr Rosamund Hill, Sarah Cahill and Suzanne Vale

The focus during our first 1.5 years of operation was to establish the Foundation, spread awareness of our existence and build a community of people with migraine, their carers and clinicians who treat migraine.

3 Community Impact

Impact no. 1

Migraine in Aotearoa New Zealand (MiANZ) Survey

Impact no. 2

Ministry of Health: 2023/24 Health Survey Questions

Impact no. 3

Pharmac Application

MIGRAINE FOUNDATION
Aotearoa New Zealand

Impact no. 4

Emgality Advocacy Toolkit

Impact no. 5

Inaugural migraine information evening

Impact no. 6

Celebrating our 1st birthday

Impact no. 7

Website resources

research

Our journey starts with research to obtain data.

We have to find out about and understand the burden of migraine disease in Aotearoa New Zealand in order to effectively reduce it.

Community Impact

3.1 Migraine in Aotearoa New Zealand (MiANZ) Survey

research
PILLAR

IN 2022 WE CONDUCTED OUR FIRST ONLINE SURVEY OF PEOPLE WITH MIGRAINE IN AOTEAROA NEW ZEALAND

THE AIM WAS TO COLLECT DATA ON THESE TOPICS:

- chronic migraine
- medication overuse
- types of acute & preventive medications used
- disability from migraine
- non-medication acute & preventive treatments used
- impact of migraine on work
- health services: use, access & experiences
- experiences of stigma
- what could be improved for people with migraine

THIS IS HOW WE DID IT, AND HOW WE'VE USED THE DATA SO FAR

DEVELOPMENT	ANALYSIS
The survey was developed using existing questions, specifically:	Data analysis began late 2022 & continued into 2023. From this, the survey data has been used to:
The Migraine Identification test (ID-Migraine TM)	**Publish 23 Key Insight Reports on our website**
The Migraine Disability Assessment Scale (MIDAS)	**Support our application to Pharmac to fund Emgality**
Demographic questions used by Stats NZ and the Ministry of Health	**Present a poster at the GP23 Conference on migraine stigma**
Qualitative (open-ended) questions	**Present our webinars**

DATA ANALYSIS AND DISSEMINATION OF THE RESULTS ARE CONTINUING

Key insight reports

We have published 23 key insight reports from the survey. To date, we've used the survey results as a New Zealand evidence-base in our Emgality application to Pharmac, have published a paper on the impact of migraine, and have had a 4th year medical student analyse results on access to health care for publication.

579

total responses received

530

responses analysed

(after removal of incomplete responses & those unlikely to have migraine)

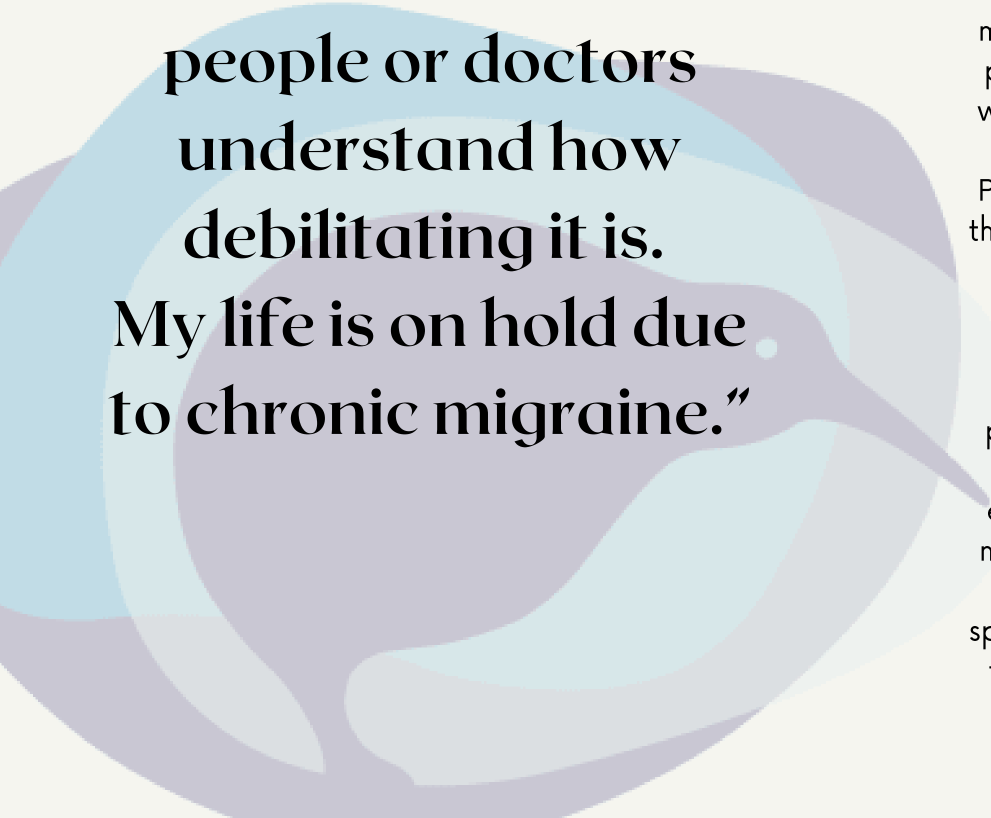
23

Key Insight Reports written & published on our website

DURING THE SURVEY, RESPONDENTS HAD THE OPPORTUNITY TO PROVIDE COMMENTS ABOUT THEIR EXPERIENCE OF LIVING WITH MIGRAINE

“It is devastating not to have access to targeted medication. I have considered going to Australia for preventatives. I know others for whom this was a factor in them relocating to Australia. Migraine is often treated as "just a headache" by medical professionals, particularly at A & E.”

"Finding a solution can be impossible. There's also not much knowledge on types of migraine. They treat them as a whole rather than on a scale. I've had many types of migraine and they have changed over my life so I know there is a spectrum/different symptoms."



“I don't think most people or doctors understand how debilitating it is. My life is on hold due to chronic migraine.”

"People do not understand the massive toll that migraine takes on people's lives. Perhaps if they did, we would have access to targeted medications. I feel let down by Pharmac as a woman and feel like the reason migraine treatments and preventatives are given a low priority is because people still believe migraine is "just a headache" and sufferers are primarily women. I am not able to be the parent, the wife or the employee that I would be without migraine. I am not able to plan for anything or take part in team sports/events because I always feel that if people are relying on me I will let them down."

“In the past, I’ve been given the impression by some health professionals that I get migraine because of something that I’m doing/not doing. If a treatment wasn’t helpful, the ‘blame’ lay with me.”

"I have tried numerous medications over many years. The side effects have impacted on my life dreadfully, in some cases rendering me unable to work as I pushed through the trial period. I continue to have chronic migraine."

"As a single parent, losing work days to migraine causes financial strain and low mood due to feeling inadequate and unreliable to my colleagues. The toll migraine headaches take on a person's mental health is devastating and severely overlooked. You feel useless and worthless because you can't provide. Even completing daily household tasks can be challenging when you feel so unwell. It's very isolating when you have chronic migraine that keep you shut away in the dark and in silence. Your self worth takes a dive."

"When I was first diagnosed with migraine it took several years to get diagnosed – often told it was allergy/sinus infection or neck muscle problems. I had to do a lot of research myself over the years to find the best treatments. I would hope that now more doctors would diagnose more quickly and have an awareness of the best treatments to offer, both medical and non-medical.”

Community Impact

3.2 Application to include migraine in the 2023–2024 NZ Health Survey

research
PILLAR

ON 14 JULY 2022 WE SUBMITTED AN APPLICATION TO THE MINISTRY OF HEALTH TO INCLUDE QUESTIONS ABOUT MIGRAINE INTO THE 2023/24 NEW ZEALAND HEALTH SURVEY

Migraine & the New Zealand Health Survey

The New Zealand Health Survey is the major national survey on all matters relating to health and healthcare.

The last time migraine was asked about in the New Zealand Health Survey was in 2013/14, and the results were never published.

The 2013/14 survey results likely under-estimated the prevalence of migraine in New Zealand because it only asked people to report migraine diagnosed by a doctor.

This application was reviewed and supported by Professor Debbie Hay, Dr Calvin Chan, the Neurological Foundation and the New Zealand Pain Society.

We asked for 2 sets of questions about migraine to be included in to the 2023/24 Survey:

1. First, **a set of validated questions** that would more accurately identify people currently affected by migraine, by asking about the experience of headache, and then other migraine symptoms.
2. Second, **questions to establish the frequency of headache**, which would give the first ever national estimate of chronic migraine in New Zealand, and several other questions to assess the **burden and impact** of migraine.

Dr Fiona Imlach and Dr Calvin Chan liaised with the Ministry of Health about the application and the results from testing the new survey questions.

THE FINAL SURVEY CONTENT WAS CONFIRMED IN JUNE, AND INCLUDED THE SET OF VALIDATED MIGRAINE QUESTIONS WE REQUESTED.

It will also include the previous 2013/14 survey question about doctor-diagnosed migraine.

These are now being asked in the 2023/24 round of the survey and should be available for analysis in 2025.

The inclusion of these questions in New Zealand's major national health survey is another key step towards understanding migraine in Aotearoa New Zealand

Our request for the inclusion of the second set of questions on the frequency and burden of headache was not successful.

To get closer to our vision **to minimise the health, economic and social burden of migraine in Aotearoa New Zealand,** we first must understand that burden.

This will be the focus of future research endeavours.

New Zealand Health Survey

The New Zealand Health Survey (NZHS) provides information about the health and wellbeing of New Zealanders. The NZHS became a continuous survey in 2011, enabling the publication of annual updates on the health of New Zealanders.

New Zealand Health Survey 2022/23
The latest results from 2022/23 New Zealand Health Survey have been published. The Annual Data Explorer presents survey results on the health of New Zealanders and allows results to be compared to previous years, and to be viewed by gender, age group, ethnic group, disability status and level of neighbourhood deprivation.

support

advocacy & awareness

The next stages of our journey are support, and advocacy & awareness.

Community Impact

3.3 Pharmac Application to fund Galcanezumab (Emgality)

support PILLAR

ON 25 NOVEMBER 2022 WE SUBMITTED A CONSUMER APPLICATION TO PHARMAC TO FUND EMGALITY FOR THE TREATMENT OF CHRONIC MIGRAINE

Emgality is one of several monoclonal antibody (mab) medications that act to block a protein, calcitonin gene-related peptide (CGRP), which is involved in triggering migraine attacks. Together, these types of medications are known as CGRP monoclonal antibodies or “**CGRP mabs**” for short.

Our application to Pharmac aimed to support people with migraine disease to access a safe medication that’s been developed specifically for migraine disease.

About CGRP mabs

CGRP monoclonal antibodies are the first medications developed specifically to prevent migraine.

Prior to their development, the only preventive medications used for migraine were medications developed for other conditions, such as depression, epilepsy and high blood pressure, that were found to be useful to prevent migraine.

The trouble with using medications that weren't designed to treat migraine includes them having significant side effects, which many people can't tolerate, and their relatively low effectiveness. They’re only effective in around half of people who try them and effectiveness can wear off over time.

CGRP monoclonal antibody medications are a significant development in migraine treatment. They’ve been found to be safe and effective, with fewer side effects than many other preventive migraine medications.

The first funding application to Pharmac for a CGRP mab was for Aimovig in February 2021, before the formation of Migraine Foundation. The Migraine Foundation’s application for Emgality in November 2022 was the second one.

APPLICATION TO PHARMAC TO FUND EMGALITY FOR THE TREATMENT OF CHRONIC MIGRAINE

About Emgality in NZ

Emgality is funded in the other main OECD countries that New Zealand compares itself to, including Australia, Canada, the United Kingdom and the USA.

But in New Zealand, people pay around $325 per injection – 2 injections are needed at the start of treatment, then one injection every 4 weeks.

Emgality has been shown to be effective in preventing migraine attacks in people with both episodic and chronic migraine, significantly reducing the number of monthly migraine days and disability from migraine.

What we did

After submitting our application we corresponded closely with Pharmac.

To assist Pharmac, we regularly provided evidence, data and references on Emgality, other CGRP mabs and topics such as migraine treatments in NZ and overseas.

In August 2023, we met with Pharmac to discuss our application and CGRP mabs. Pharmac invited us to their Neurological Advisory Committee meeting to present on the lived experience of migraine in NZ.

We compiled stories from our community into a 100+ page book of experiences of migraine, with and without access to CGRP mabs. We gave the book to Pharmac and the Committee when we presented at their meeting in September 2023.

Why we did it

Treating migraine is about lessening migraine attacks so people with migraine disease can live their lives.

Migraine takes your life while you're living it. Lessening the frequency, intensity or duration of migraine attacks enables people with migraine to live life fully.

New Zealanders deserve the effective and targeted migraine medications that people overseas can access.

Although Emgality was made available in NZ in August 2022, the manufacturer had not made a funding application to Pharmac nor committed to making one.

Our impact

Our consumer application to Pharmac meant that Emgality was considered for funding in 2023.

Our request to improve timeliness and efficiency by considering all the anti-CGRP medications together by Pharmac's Neurological Advisory Committee was granted.

Our patient stories made an impression - the Committee Chair told us "the stories were heart-breaking."

Pharmac expanded the scope of anti-CGRP medications to include episodic as well as chronic migraine.

34

Migraine stories
told for the first time
across 108 pages

New Zealanders'

Presented to Pharmac & the Neurological Subcommittee to communicate
the lived experience of migraine in Aotearoa New Zealand

Compiled by

MIGRAINE FOUNDATION
Aotearoa New Zealand

New Zealanders' stories of MIGRAINE DISEASE & CGRP MEDICATIONS

RESUMING LIFE

Anonymous

I had my first migraine attack when I was 18 years old and this continued to occur every few months over the course of the next few years, infrequent but troublesome when they occurred.

This changed when I was around 27 years old and experienced a migraine attack that never disappeared.

Triptans worsened my migraine attacks and I experienced severe enough side-effects with Topiramate so I had to stop using it.

My neurologist prescribed Emgality.

Within the first few days of starting treatment, I had a noticeable decrease in the migraine pain and other symptoms.

In the month following the first set of injections, I was able to get out of bed and carry out the majority of my household activities for the first time in months.

Following the second dose, I was able to leave my house, and socialise, with the pain continuing to decrease.

Even with the support however, it has meant reprioritising and reorganising my spending and reducing some expenses in other areas.

Emgality has made a massive difference to my health and wellbeing, and I do not wish to consider how my health would likely have continued to deteriorate without it.

It has allowed me to increasingly resume the normal activities that migraine was stripping away from me. It has enabled me to be able to support family, socialise with friends, and will allow me to soon again resume my nursing career.

THANKFULLY EVERYTHING CHANGED

By Caitlyn Kolumban

LIFE CHANGING

But it took time

By Fiona Imlach

My history of migraine was one of relentless and impervious progression.

I tried a host of preventives:

Tricyclic anti-depressants made me too sedated to function, not to mention constipated; and they didn't work.

Beta-blockers made it impossible to walk uphill without feeling like I was about to pass out, not to mention the nightmares; and they didn't work.

Sodium valproate made me fat; and it didn't work.

Pizotifen did work, but I was falling asleep at my desk. It wasn't compatible with employment.

Topiramate worked for a while, then stopped working, and gave me an ear-worm of *Love Is All Around* ("I feel it in my fingers, I feel it in my toes") because of the persistent sharp tingling in my hands and feet.

MIGRAINE BY NUMBERS

By Amanda Lowe

WHAT IS THIS WONDER?

By Dr Jamie Mātenga Wood

MY KIDS NOW HAVE A BRIGHTER FUTURE THAN THEIR ANCESTORS

By Sarah Cahill

Migraine disease has affected my family for generations. My great grandmother, grandmother, mother, aunties and cousins have all lived, and live with this debilitating neurological condition.

I have also married into a family who has migraine.

I watch my nieces complain of head pain and wonder if this next generation of my family are destined for a life of pain, nausea and vomiting, and managing the effect migraine has on school, study and career opportunities.

SINCE I HAVE BEEN ABLE TO

By Amee Parker

Kia ora,

I am Amee, a 41-year-old Pākehā female. I am a recent PhD graduate from the University of Otago and a mother of a seven-year-old. I first experienced a full-blown migraine attack twelve years ago.

A KIWI REFUGEE

By Kirilee Beil

My husband and I would love to move our family back to NZ, but not having guaranteed and funded access to Aimovig is an insurmountable barrier to our returning to work as registered nurses in NZ.

435 ANONYMOUS KIWIS

In October 2022, Migraine Foundation Aotearoa New Zealand conducted an online survey of people with migraine in Aotearoa. The survey included an open-ended question about CGRP mab medications. Of the 530 survey respondents, 435 answered this question, and from those 435 answers, four themes emerged.

The question was:

Aimovig, Emgality, Ajovy and Vyepti are a new class of migraine prevention medication developed specifically to target migraine (calcitonin gene-related peptide or CGRP monoclonal antibodies). They have fewer side effects than most other preventive medications.

Only Aimovig and Emgality are currently available in New Zealand.

- ***If you have ever tried one of these, please tell us about your experience.***

theme 1

People are desperate for something that will reduce the severity and impact of their migraine attacks and improve their lives

"I'd try anything"

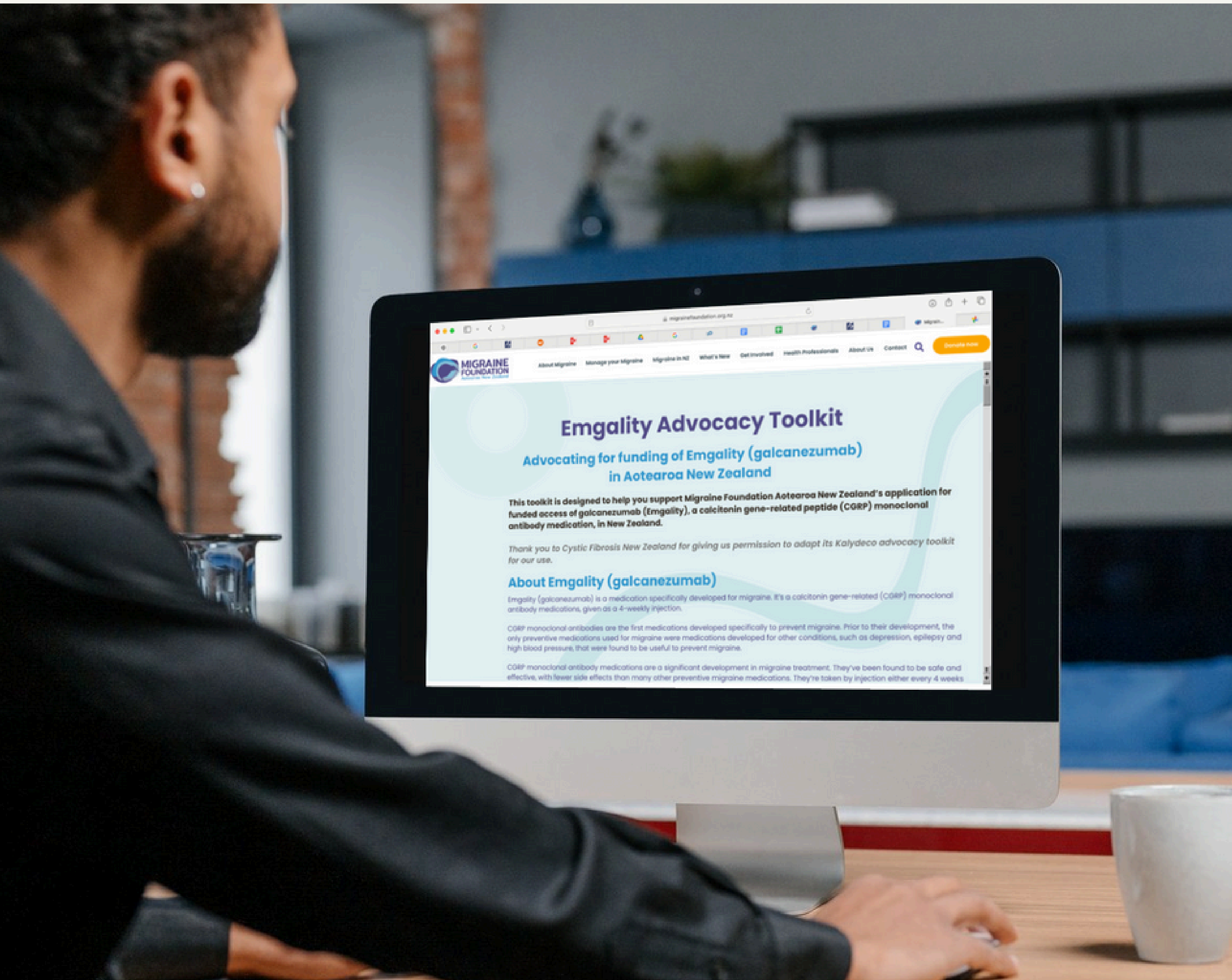
Community Impact

3.4 Emgality Advocacy Toolkit

advocacy & awareness
PILLAR

ON 29 NOVEMBER 2022 WE LAUNCHED OUR EMGALITY ADVOCACY TOOLKIT

The toolkit was designed to help people in Aotearoa New Zealand support our application to Pharmac to fund Emgality, and raise awareness of migraine and the vital need for improved access to modern migraine medications.



Emgality Advocacy Toolkit

Advocating for funding of Emgality (galcanezumab) in Aotearoa New Zealand

This toolkit is designed to help you support Migraine Foundation Aotearoa New Zealand's application for funded access of galcanezumab (Emgality), a calcitonin gene-related peptide (CGRP) monoclonal antibody medication, in New Zealand.

Thank you to Cystic Fibrosis New Zealand for giving us permission to adapt its Kalydeco advocacy toolkit for our use.

About Emgality (galcanezumab)

Emgality (galcanezumab) is a medication specifically developed for migraine. It's a calcitonin gene-related (CGRP) monoclonal antibody medications, given as a 4-weekly injection.

CGRP monoclonal antibodies are the first medications developed specifically to prevent migraine. Prior to their development, the only preventive medications used for migraine were medications developed for other conditions, such as depression, epilepsy and high blood pressure, that were found to be useful to prevent migraine.

CGRP monoclonal antibody medications are a significant development in migraine treatment. They've been found to be safe and effective, with fewer side effects than many other preventive migraine medications. They're taken by injection either every 4 weeks

THIS IS A SUMMARY OF THE INFORMATION IN THE EMGALITY TOOLKIT:

IT PROVIDED BACKGROUND AND PRACTICAL INFORMATION THAT THE MIGRAINE COMMUNITY COULD USE TO ADVOCATE FOR FUNDING.

THE TOOLKIT WAS VIEWED 1,046 TIMES DURING THE ADVOCACY PERIOD & COMMUNITY MEMBERS TOLD ANECDOTES ABOUT ACTIONS THEY TOOK IN SUPPORT USING IDEAS IN THE KIT.

The toolkit was based on Cystic Fibrosis New Zealand's advocacy toolkit for Kalydeco.

Our thanks go to Cystic Fibrosis New Zealand for giving us permission to adapt its advocacy toolkit for our use.

About Emgality

What it is
How it works

How medications are approved & funded

Key messages on impact of migraine & Emgality

Advocating know-how

Social Media
Emailing Pharmac
Meeting your local MP
Talking with the Media

Templates & connecting

Social media posts
Sample correspondence
Key people

Community Impact

3.5 Inaugural Migraine Information Evening

information
PILLAR

IN AUGUST 2023 WE HELD OUR FIRST MIGRAINE INFORMATION EVENING IN AUCKLAND.

“TALKING MIGRAINE” SHOWCASED GUEST SPEAKERS NEUROLOGIST DR ROSAMUND HILL & PAIN SPECIALIST DR PAUL VROEGOP.

MIGRAINE FOUNDATION
Aotearoa New Zealand
is pleased to present:

TALKING MIGRAINE
Your questions answered

Our first in-person Migraine Information Evening with guest speakers, **Neurologist, Dr Rosamund Hill** and **Pain Specialist, Dr Paul Vroegop** followed by a panel Q&A facilitated by **Journalist, Celia Whitley**.

DR ROSAMUND HILL
Neurologist

DR PAUL VROEGOP
Pain Specialist

Facilitated by
CELIA WHITLEY
Journalist

WEDNESDAY 16 AUGUST 2023
6:30 PM EPSOM COMMUNITY CENTRE EPSOM HALL
202 GILLIES AVE | EPSOM AUCKLAND

TICKETS AVAILABLE ON
eventfinda

migrainefoundation.org.nz
eventfinda.co.nz/2023/talking-migraine/auckland/epsom

38

people attended our first in-person event

3

hours of specialist knowledge on managing migraine & chronic pain

In response to our promotion of the event, 38 people gathered at the Epsom Community Centre to hear the two migraine experts speak from two complementary specialist perspectives.

DR HILL GAVE AN OVERVIEW OF THE DIFFERENT TYPES OF MIGRAINE, WAYS TO TREAT ACUTE MIGRAINE ATTACKS, INFORMATION ON MEDICATIONS & DOSES AND THE USE OF PREVENTIVE MEDICATION.

DR VROEGOP DISCUSSED HOW CHRONIC PAIN CHANGES THE BRAIN AND THE MANY WAYS IN WHICH WE CAN HELP OUR BRAIN WHEN WE HAVE CHRONIC PAIN.

An hour of questions followed, and we gave away a door prize.

Afterwards, people lingered longer than expected, sharing and connecting over their migraine experiences.

information

leadership & sustainability

We round out with information, and with leadership & sustainability, checkpointing through the last of our pillars of service in our first reporting period. But we're just getting started on the next leg of this epic quest!

Community Impact

3.6 Celebrating our first birthday

leadership & sustainability
PILLAR

ON 1 APRIL 2023 WE CELEBRATED OUR FIRST BIRTHDAY

Consistent with the advice that people with migraine receive to moderate their lifestyles, instead of clinking champagne and chowing into cake, we took a moment to catch our breath and meditate on the happy moments over the past year.

It felt like a slow birth, but it was only five months from our first online meeting of our three co-founders at the end of October 2021 until we were registered as an Incorporated Society on 21 March 2022 and our website went live on 1 April 2022.

From our launch, it was a baby with a relentless appetite that we raced to keep fed!

We also celebrated by giving our community the presents by giving away five copies of one of our favourite books, Managing Your Migraine, by Dr Katy Munro, to some well-deserving migraine community members.

We also asked our community this question as part of our first birthday celebrations. The answers spoke to the positive impact we've had for many people living with migraine.

"HOW HAS MIGRAINE FOUNDATION AOTEAROA NEW ZEALAND HELPED YOU IN OUR FIRST YEAR?"

"By providing a centralised resource base and advocacy voice for the NZ context of migraine needs. SOOO NEEDED!!!

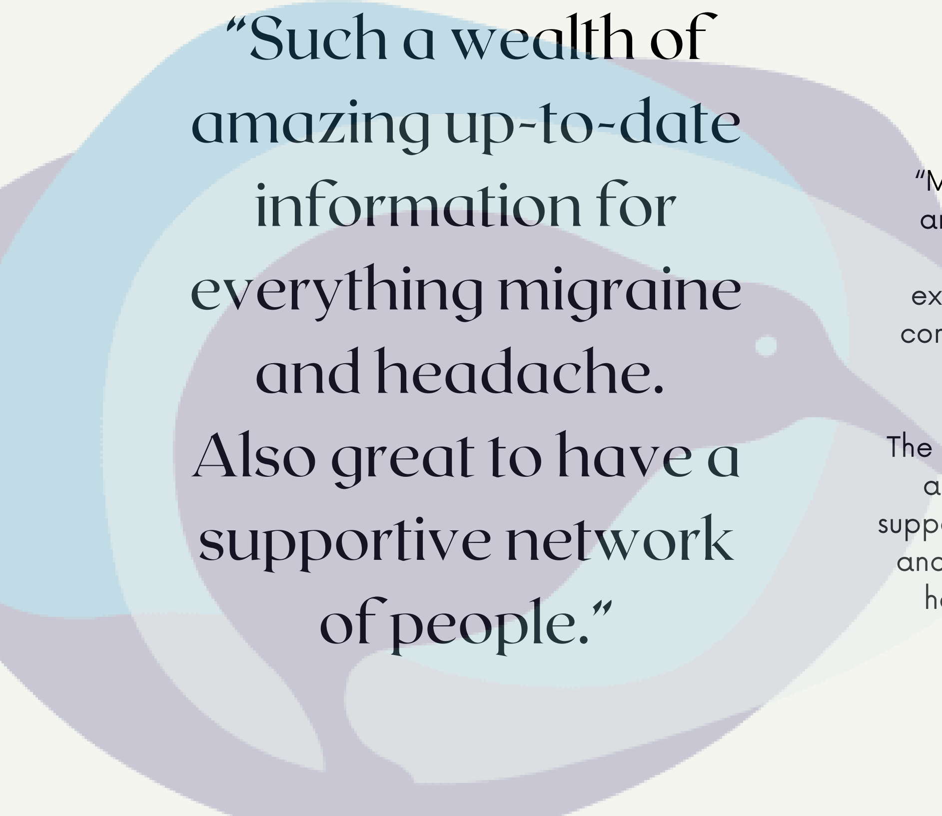
Things like that page of info re medications in NZ is really useful. Obviously the Emgality advocacy.

Loving the relationships you're building with clinicians to provide credibility and clinical oversight of info."

"The Facebook group has been really helpful to keep me up-to-date with recent information about all things migraine, get some tips on relief and information on medications.

The content in Migraine Foundation NZ socials have been helpful to help me prep for when I need to talk to my GP and my workplace.

Honestly you have been super helpful! Thanks so much for your work :)"



"Such a wealth of amazing up-to-date information for everything migraine and headache. Also great to have a supportive network of people."

"Migraine can be a very isolating illness and there is little understanding of how debilitating it is by those who don't experience migraine, so to have found a community of people who understand and provide compassion is invaluable.

The Foundation's Facebook support group is also a great source of information and support when I need advice, a frustrated vent and to share experiences of what has, and hasn't been helpful. I've learnt so much reading other's experiences on that page."

"The Migraine Foundation's website is my place to go to keep informed about the latest developments in migraine treatment. I've found the website with its comprehensive, well researched information about everything related to migraine incredibly helpful."

"It's been wonderful to have found a community of fellow migraine sufferers.

I no longer feel so isolated. My struggles with this illness have been validated by others who experience the same and understand.

Meeting others who experience migraine at Ozone cafe and sharing experiences was a great experience."

"It has helped to feel less alone and confused.

It has created a community of those experiencing migraine that wasn't known to me before.

It has provided really useful and helpful info through posts and blogs to be educated and create a better understanding of what I'm experiencing and how/what can help.

The one Zoom I attended gave me hope and was the first time I felt it was so relatable I felt heard and validated – especially hearing that someone else has the same kind of migraine – can't remember meeting anyone else before that who has the same type.

Thank you for your important and incredible work."

"Knowing that the Migraine Foundation is advocating for improved accessibility to Emgality is very heartening.

I'm so very grateful for the time, energy and advocacy efforts of Sarah, Suzanne and Fiona in setting up and running this incredibly helpful organisation. It's a huge source of invaluable support!!"

"You've allowed me to not feel so much guilt for having migraine, accepting it's part of my life and that I can work alongside it.

Your social media and Facebook community page have really helped with my use of language and describing them to others – making sure I am not downplaying the serious nature of the condition and ensuring I communicate with my partner, friends and workmates with honesty and directness."

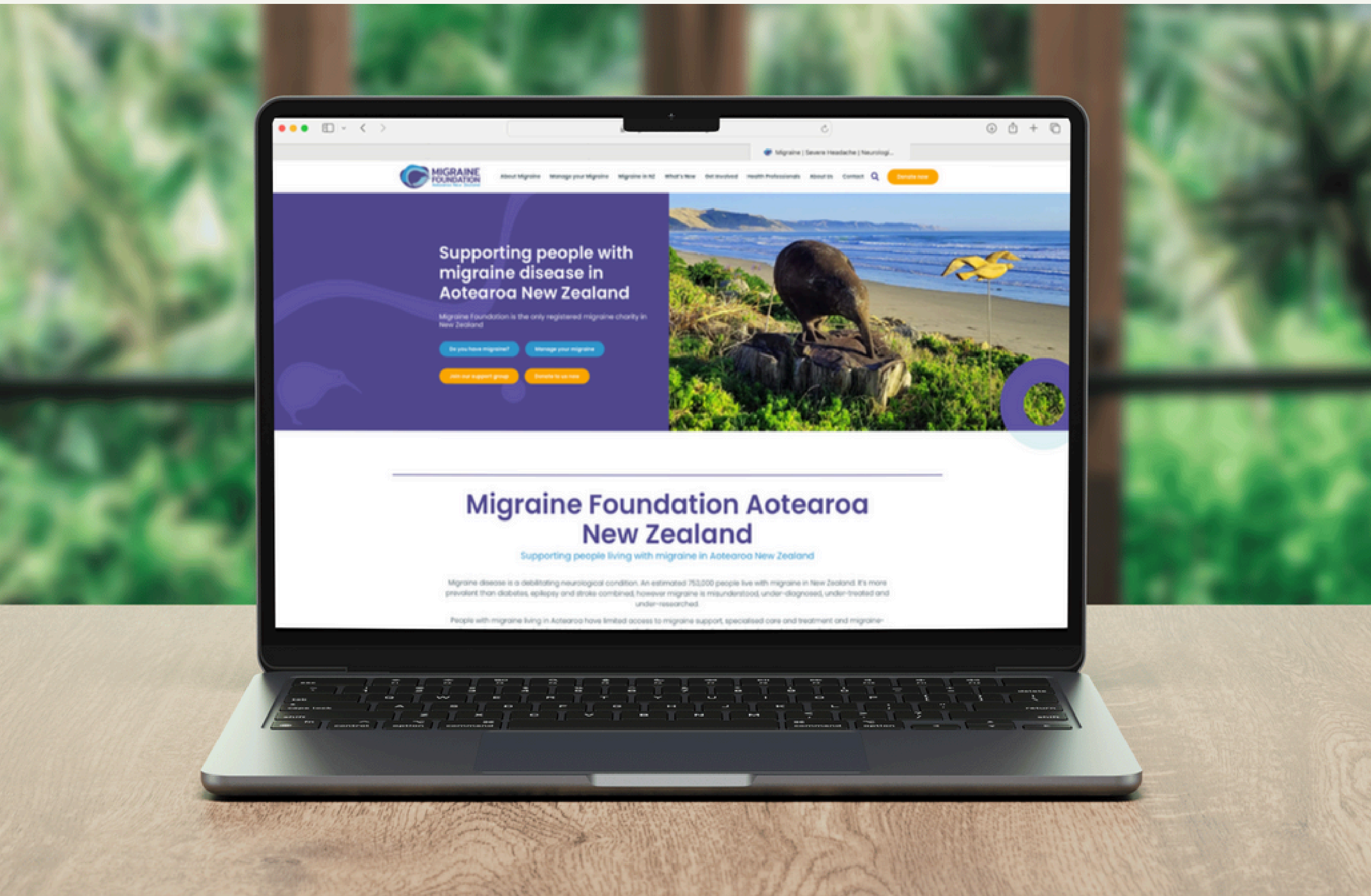
Community Impact

3.7 Migraine Foundation Aotearoa New Zealand website

information
PILLAR

ON 1 APRIL 2022 WE LAUNCHED OUR WEBSITE: MIGRAINEFOUNDATION.ORG.NZ

OUR WEBSITE PROVIDES INFORMATION ABOUT MIGRAINE AND ITS MANAGEMENT THAT IS UP-TO-DATE, RELEVANT TO NEW ZEALANDERS AND ENDORSED BY OUR CLINICAL ADVISORY GROUP.



Supporting people with migraine disease in Aotearoa New Zealand

Migraine Foundation Aotearoa New Zealand

Supporting people living with migraine in Aotearoa New Zealand

62

latest news articles published on our website

2+3

Patient resources developed

Health professional resources developed

1 Aug - 31 Oct '23

48,459

website views

19,005

website users

Top Pages Viewed

1. Migraine medication options
2. Current issues & challenges
3. I tried Aimovig for 6 months. Here's my verdict
4. Latest news
5. Emgality FAQs
6. The team
7. Migraine in NZ Survey Insights
8. About migraine
9. Emgality advocacy toolkit
10. Migraine in NZ survey

Our website is also where we publish new information about migraine and updates of our work. These have included:

- Results of our Official Information Act request on the number of people on a benefit for migraine (only 429 at June 2022).
- Results from the 2013/14 New Zealand Health Survey that were not published, but we requested. These gave the overall prevalence of doctor-diagnosed migraine in NZ as 16% and the same for Māori.
- Our letters and responses from Pharmac regarding our concerns about their processing of funding applications for CGRP mabs.

4 Performance Report

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MIGRAINE FOUNDATION AOTEAROA NEW ZEALAND'S FIRST ANNUAL PERFORMANCE REPORT FOR YEAR END 30/4/2023

Ciick this link to view the full Annual Performance Report on Charities Services' website:

https://register.charities.govt.nz/CharitiesRegister/ViewCharity?accountId=953cedc7-5e09-ed11-bb15-0022480ffcd1&searchId=d10b0800-86c0-4374-9052-594933b1862d

5 Our Team

Sarah Cahill – Cofounder and Chair
Fiona Imlach – Cofounder and Deputy Chair
Suzanne Vale – Cofounder and Secretary/Treasurer
Jane Bollard – Charity Sector Advisor
Sue Garrett – Researcher

CLINICAL ADVISORY GROUP MEMBERS

Dr Rosamund Hill
Dr Desiree Fernandez
Dr Ray Bose
Dr Paul Vroegop

STUDENTS

Katie Ensor
Ella McCool-Reay
Aria Malone
Tamsyn Curin

As at 31 October 2023

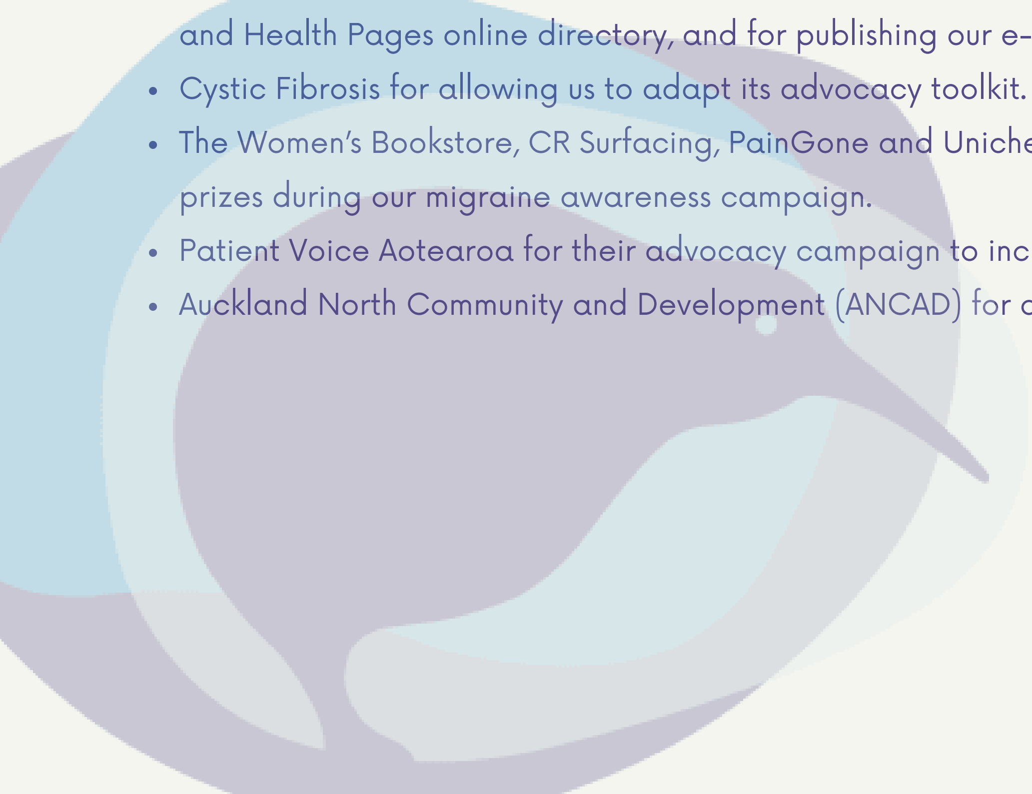
Migraine Foundation Aotearoa New Zealand is a member of the New Zealand Neurological Alliance, and the International Headache Society Global Patient Advocacy Coalition (IHS-GPAC)

6 Supporters & Funders

DURING OUR FIRST 1.5 YEARS, WE WERE FINANCIALLY SUPPORTED THROUGH DONATIONS AND A GRANT.

THANK YOU TO THE ORGANISATIONS & FUNDERS WHO HAVE SUPPORTED US IN OUR FIRST 1.5 YEARS

- The Lion Foundation for a grant to redevelop our website.
- Fusion5 for a generous donation from a silent auction.
- GoGenerosity and The Renew Room for your time & experience to support our branding and collateral development.
- Rocketspark for supporting the ongoing monthly cost of hosting our website.
- Helen Bowler Designs for logo design support.
- Cervin Ltd for sponsoring our advertisement in its Primary Health & Wellbeing Directory and Health Pages online directory, and for publishing our e-learning course for GPs.
- Cystic Fibrosis for allowing us to adapt its advocacy toolkit.
- The Women's Bookstore, CR Surfacing, PainGone and Unichem Cuba Mall for donating prizes during our migraine awareness campaign.
- Patient Voice Aotearoa for their advocacy campaign to increase funding for medicine.
- Auckland North Community and Development (ANCAD) for accounting support.



THANK YOU TO EVERYONE IN OUR MIGRAINE COMMUNITY WHO SUPPORTED US THROUGH A DONATION THIS YEAR.

Your support has been invaluable and ensures migraine has a voice in Aotearoa New Zealand.

ALSO THANK YOU TO:

Our Clinical Advisory Group members and founding members for your support, to the students who joined us during 2022-23 and to:

- New Zealand Pain Society
- Neurological Foundation
- Healthify
- Dr Calvin Chan
- Professor Debbie Hay

1.5

years of operation

3

volunteer co-founders, each living with migraine

4

volunteer health professionals in our Clinical Advisory Group

753,000

people living with migraine disease in Aotearoa

888

Facebook online support group members

476

monthly newsletter subscribers

4

undergraduate students hosted

530

survey responses analysed

10

community in-person meetups of people with migraine disease held

1

in-person event held with guest speakers, Dr Rosamund Hill and Dr Paul Vroegop

3

webinars presented:
My Health Hub
New Zealand Pain Society
NZ Pharmaceutical Society (AKL branch)

1

online community meet-up catering for people with migraine who struggle with going out

23

monthly newsletters sent to a growing number of subscribers

MIGRAINE FOUNDATION
Aotearoa New Zealand

5

press releases published raising awareness of migraine disease and reducing stigma

23

MiANZ Key Insight Reports written & published on our website

62

latest news articles published on our website

2

patient resources developed

3

health professional resources developed

2

awareness campaigns

Compiled & written by: Sarah Cahill & Fiona Imlach
Designed by: Suzanne Vale
Migraine Foundation Aotearoa New Zealand (Charity number: CC60312)

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info@migrainefoundation.org.nz