CARDIOMYOPATHY Australia New Zealand

NEWSLETTER | AUGUST 26

Hello everyone,

Welcome to our winter newsletter. I hope you're avoiding winter bugs and staying healthy. What a busy period for our small volunteer team! In this edition, you'll read about our new website: cmanz.org.au We're beyond proud of it. Please check it out and let us know your thoughts. This is our first release – we're undergoing review and will add more content steadily.

We're excited to let you know we've led some research into women's experiences of cardiomyopathy care, which has been accepted at the Cardiac Society of Australia and New Zealand (CSANZ). I'll be presenting it at the annual scientific meeting over the weekend 7-9 August in Sydney. A moment made more special for me personally by the fact this is the 5th anniversary of receiving my heart transplant – I got my call on the 8th and was transplanted on the 9th. To be presenting patient-led research at Australia's largest cardiology scientific conference 5 years later is unbelievable to me, and I honor my donor and their family for giving me this life full of interesting opportunities, and the ability to contribute for our cardiomyopathy community.

We've heightened the visibility of cardiomyopathy with involvement in an important Federal Government Ministerial Expert Panel forum on women's cardiovascular disease – four women attended and contributed their perspectives to this important conversation.

We also bring you information on new genetic therapy and medication trials under way. As always, we provide news about trials in order to keep the community informed, but importantly, we acknowledge that not all trials are going to be successful, and that if they are, there are drawn-out regulatory approval and price negotiation processes before any therapies are available. We don't want to raise false hope - rather provide insight to the slow and steady progress being made.

We celebrate a big milestone for our online support group, now over 1000 members, and highlight the wonderful team at Kilkivin Show and Campdraft society, who kindly chose us as their charity to support this year.

We hope you enjoy this newsletter.

Leigh

Leigh Bell
President, Cardiomyopathy Australia New Zealand

Our NEW Website is live!

We are excited to let you know about our new Cardiomyopathy Australia New Zealand website: cmanz.org.au We wanted to create a trusted place where people living with cardiomyopathy, their families and health professionals can find up-to-date, clear, practical and evidence-based information.

This has been a true community effort. We are grateful to the Heart Foundation for their supporting the project through review of the medical information, and to the volunteers, clinicians and community members who have generously contributed their time and expertise. Thank you to those big-hearted folk who told their story in our Community Voices section – this is a wonderful corner of the website which we'll grow over time. (If you told your story and it isn't yet uploaded, please bear with us – time constraints meant we didn't get to every contribution, but we will!).

Check out our downloadable, printable Information Sheets on each type of cardiomyopathy. These are something our community has been asking us for. It's very pleasing to be delivering this suite of resources, and we hope you find them useful for learning more, and for sharing with family, friends, workplaces etc should you wish to explain a little about your condition.

The website has launched as a beta version while we complete a final review. We are now inviting feedback from both our community and health professionals to help us identify any improvements. **We'd love your feedback!** We'll consider and prioritise any improvement ideas for our next release. Please click the links below to share your feedback with us ...

Patients, Families + Carers

WEBSITE FEEDBACK SURVEY

Clinicians + Heath Professionals

WEBSITE FEEDBACK SURVEY

info@cmanz.org.au

CMANZ Research Accepted for CSANZ

We are delighted to let you know that CMANZ's patient-led research has been accepted for presentation at the **Cardiac Society of Australia and New Zealand (CSANZ) Annual Scientific Meeting** this August. This meeting is the major annual cardiology conference for Australia and New Zealand, and to have our patient voice so strongly visible is wonderful for our community. It's the first time CMANZ has been involved in this type of research, and we're thrilled to see the voice of patients brought to this major forum.

The abstract explores the experiences of women living with cardiomyopathy through the Global Heart Hub's International Patient Expert Committee (IPEC2) project, highlighting issues including diagnosis, pregnancy, menopause and the psychosocial impacts of living with a heart muscle disease. We'll share the poster on our website once it's ready.

The project demonstrates the value of consumer-led research and the importance of ensuring lived experience informs future healthcare, research and policy. Most importantly, this research would not have been possible without the women who generously shared their experiences. **Thankyou to every participant for helping ensure the voices of people living with cardiomyopathy are heard.**

Australian Government Women's Health Roundtable

CMANZ was pleased to be invited to the Australian Government Women's Heart Health Roundtable in Sydney, supporting the work of the Ministerial Expert Panel on Women's Health. The roundtable brought together clinicians, researchers, consumer representatives and advocacy organisations to discuss how care for women with heart disease can be improved across Australia. Key themes included improving recognition of women's symptoms, reducing delays in diagnosis, ensuring equitable access to specialist care, increasing public awareness and strengthening the inclusion of women in cardiovascular research. Cardiomyopathy presents unique challenges for many women throughout their lives, including during pregnancy and menopause.

The CMANZ Team with Assistant Minister for Women The Hon Rebecca White MP

It was important that these experiences were represented as national priorities continue to develop. The voice of cardiomyopathy patients has never been stronger, with four attendees providing their insights. CMANZ looks forward to continuing to contribute the voice of people living with cardiomyopathy to these important discussions.

Cardiomyopathy Research Update

Hypertrophic Cardiomyopathy Research Update

Aficamten Phase 3 Results
Researchers have announced positive results from the Phase 3 ACACIA-HCM clinical trial investigating aficamten for people living with symptomatic non-obstructive hypertrophic cardiomyopathy (nHCM). Until now, treatment options for people with non-obstructive HCM have largely focused on managing symptoms, with few therapies developed specifically for this group. In the trial, participants receiving aficamten reported improvements in symptoms, quality of life and exercise capacity compared with those receiving placebo. While these findings are encouraging, aficamten is not yet approved for this indication and remains under review by regulatory authorities. Further assessment and if successful, approval and funding negotiations, will determine whether it becomes available as a treatment option in Australia and New Zealand.

MyPeak-1 genetic therapy
One of the first human gene studies, MyPEAK-1, is investigating TN-201, a gene therapy designed for people with hypertrophic cardiomyopathy caused by certain MYBPC3 gene variants. Rather than treating symptoms, the therapy aims to replace the faulty genetic instructions responsible for the condition. Although still in the earliest stages of clinical research, and several years away from routine practice, the study represents an important milestone. Researchers are first assessing safety before determining whether the treatment can improve heart function over time.

EDG-7500 Phase 2 results
Meanwhile, recent positive results were announced in a Phase 2 trial of a novel oral medication, EDG-7500 for obstructive and non-obstructive HCM. After 12 weeks there were consistent improvements for those with both types of HCM, with no additional heart failure risk.

Gene Therapy Research Expands for Arrhythmogenic Cardiomyopathy

Researchers are also making progress in developing gene therapies for arrhythmogenic cardiomyopathy (ACM). Several early-stage studies are investigating treatments for people with disease caused by PKP2 gene variants, one of the most common genetic causes of ACM. These therapies aim to deliver healthy copies of the affected gene to heart muscle cells. Studies are in very early phases, meaning their primary focus is to establish safety before researchers determine how effective the treatments may be. One such study under way is this phase 1 trial for example.

Although much work remains before gene therapy becomes widely available, these programs reflect growing international investment in finding treatments that target the underlying genetic causes of cardiomyopathy rather than its complications. We'll continue to bring you information as results are announced.

New Advances in LMNA Cardiomyopathy Research

Research into LMNA cardiomyopathy continues to gather momentum. A recent study published in the European Heart Journal developed an improved risk prediction model to better estimate the likelihood of heart failure progression in people with LMNA-related cardiomyopathy. More accurate prediction tools may help clinicians identify people who would benefit from closer monitoring or earlier intervention.

At the same time, researchers have just commenced the first human clinical trial investigating gene therapy for LMNA cardiomyopathy. Like other gene therapy studies, the treatment remains at an early stage and is primarily evaluating safety. The trial is being run in North America, you can learn more here.

Together, these developments represent encouraging progress towards more personalised care for people living with this rare inherited condition.

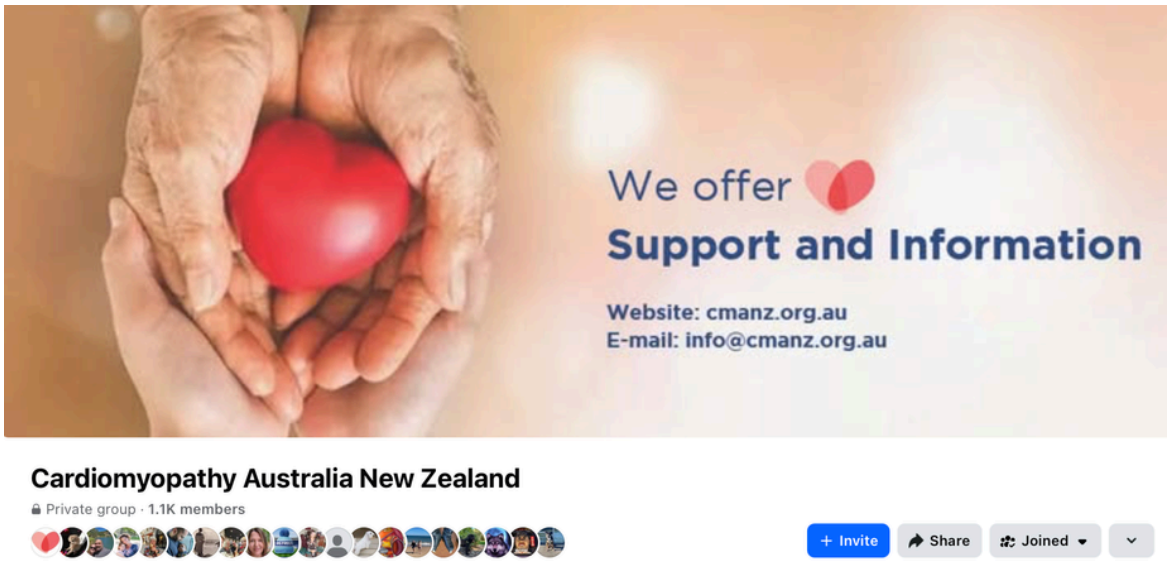
Our Private Facebook Community now 1000+

We recently celebrated an exciting milestone - our private Facebook support community has grown to more than 1,000 members! We're building a welcoming and supportive community where people living with cardiomyopathy, family members and carers can connect with others who truly understand their experiences.

A special thank you goes to our volunteer moderators Vikki, Sharn, and Bronny who generously give their time to help maintain a respectful, safe and supportive environment for everyone.

This growth means we are seeking additional moderators. The role involves approving or declining new member applications, booting out any scammers who inadvertently make in through, and keeping an eye on the page for any problematic posts. Full training is provided, and you'll be supported by a group of experienced moderators. The time commitment can be as little or as much as you like; even a few moments checking the feed when you're scrolling would be helpful. **If you have time to help us keep our group safe and active, or have any questions, please write to us at info@cmanz.org.au**

If you'd like to join, or know someone who may benefit from joining our community, new members are very welcome. Please answer the questions when prompted – we use these to ensure our community stays safe. **Join via this link**



Kilkivan Show and Campdraft Committee raises funds for CMANZ

We are incredibly grateful to be the recipients of the Kilkivan Campdraft Charity Auction. This small team from rural QLD chose CMANZ as the beneficiary due to a committee member's close connection with cardiomyopathy. **They raised an incredible $8,200!** Thank you to the bighearted committee, pictured below at the Camp Draft with CMANZ President Leigh Bell.

Upcoming Webinar

Meet the Experts - Hypertropic Cardiomyopathy

Join us for an online webinar featuring three leading Australian experts in hypertrophic cardiomyopathy:

- A/Prof Jodie Ingles
- Dr Andris Ellims
- Dr Vimal Patel

The webinar will cover diagnosis, current and treatment options, genetics, and family screening. There will also be an opportunity to submit questions. Whether you have recently been diagnosed or have been living with HCM for many years, this session will provide practical, evidence-based information from clinicians working at the forefront of patient care.

Tuesday 18 August
3–4pm AEST
Register HERE

Sisters run for Cardiomyopathy

We're proud to be the recipient of an inspiring fundraising initiative by Holly Munden, whose father lives with HCM. Holly is running in the Sydney Marathon at the end of August. She writes:

Two Marathons. Two Continents. One Mission.

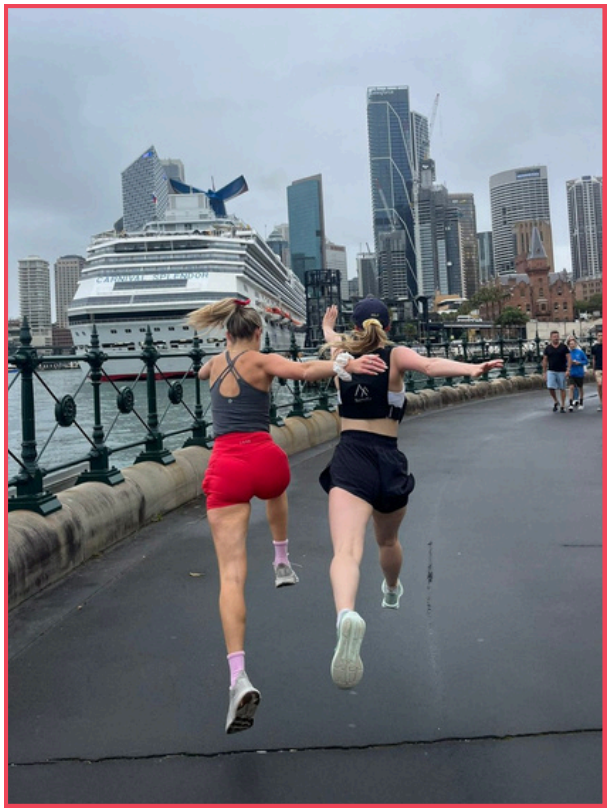
Four months apart and half a world away, my sister and I are on a joint mission to spread awareness and raise vital funds for Cardiomyopathy.

Following my sister Lucy's inspiring and incredible 42.2km run at the London Marathon, where she raised a whopping £4,500, it is now my turn to take on the challenge at the iconic Sydney Marathon.

Our dad, Tom, was diagnosed with cardiomyopathy at just 46 years old. What his doctor initially thought was routine chest pain was first suspected to be a heart attack, before being diagnosed as Hypertrophic Cardiomyopathy (HCM). I saw firsthand how my dad's life changed in an instant. Though he had always enjoyed being active through running, tennis, and racquetball, he was suddenly told to stop high-intensity sports and stick to low-paced activity. From managing strict heart rate limits to navigating the risks of high altitudes, the adjustment for him, physically and mentally, has been massive and lifechanging.

... My goal is to raise $2,000 for Cardiomyopathy Australia and New Zealand. These funds support the 1 in 250 people living with this condition, helping improve early diagnosis, treatment, and support services.

I'm doing this for my dad, for everyone living with the condition, and for my own heart's future. ❤️



You can support Holly via her Sydney Marathon fundraising link HERE

Thank you Holly for choosing to support CMANZ.

Welcome Miranda Hill

Miranda is a long-term contributor to CMANZ, re-joining the Board in 2026. She brings more than 20 years of lived experience as a cardiac patient, including undergoing a heart transplant in 2015. She is a qualified Health Counsellor and Mental Health First Aider with a strong commitment to patient-centred care, advocacy, and wellbeing. Read more here

Support CMANZ!

Everything CMANZ achieves is made possible through the generosity of our volunteers, supporters, clinicians, researchers and community.

Over the past few months we have launched a new website, expanded our information resources, contributed to national advocacy, supported research, grown our online community to more than 1,000 members and continued working to ensure the voices of people living with cardiomyopathy are heard.

As a small, volunteer led charity, we're working from our kitchen tables and spare rooms to improve cardiomyopathy care and support. Every contribution makes a genuine difference.

You can support CMANZ by:

- Making a donation via our website
- Fundraising
- Volunteering your skills or experience
- Engaging with our social media
- Sharing our information resources
- Joining our online community
- Participating in research and consumer engagement activities
- Helping raise awareness of cardiomyopathy within your own community

Together, we are building a future where everyone affected by cardiomyopathy has access to trusted information, meaningful support and a stronger voice in research, healthcare and policy.

Thank you for being part of the CMANZ community.

Interested in helping out?
Please reach out to us at info@cmanz.org.au

Community Voices

Read lived-experience stories from our community in the Support & Resources section of our new website here

Jodie's Hypertrophic Cardiomyopathy (HCM) story

June 15, 2026

My Hypertrophic Cardiomyopathy Story Hi, my name is Jodie. I am 35 years old. I am a Disability Support Worker and qualified Teachers Aide. I love my family, volunteering with

Read more >

Dino's Dilated Cardiomyopathy (DCM) story

April 9, 2026

My Journey with Dilated Cardiomyopathy Hi, my name is Dino, and I'm from Adelaide. I'm 51 years old, and was diagnosed with Idiopathic Dilated Cardiomyopathy in 2024. This is my

Read more >

Leo's Amyloid Cardiomyopathy (ATTR-CM) story

February 10, 2026

Leo's Story – Living with ATTR Wild-Type Amyloidosis Hi, my name is Leo and I am living with ATTR wild-type amyloidosis. It is a rare disease where abnormal proteins called

Read more >

Jessie's Hypertrophic Cardiomyopathy (HCM) story

February 10, 2026

Hello! My name is Jessie and I have hypertrophic cardiomyopathy. What led to your diagnosis? What has happened since then? Growing up, I was very active and played a lot

Read more >