# CARDIOMYOPATHY
# Australia New Zealand

NEWSLETTER

DECEMBER 25

## Hello everyone,

It has been a productive few months at CMANZ. We are currently preparing content for our new website, which will launch in the coming months. The updated site will offer clearer information on the different forms of cardiomyopathy, lived-experience stories, and practical guidance for day-to-day management. We look forward to sharing it with you and welcome your feedback to help us keep improving.

Our awareness campaigns are also well underway. Our first campaign focused on Amyloid Cardiomyopathy and featured a webinar with A/Prof Nikki Bart and A/Prof Elizabeth Paratz. Two further campaigns, on HCM and ACM, will run early in the new year, each supported by a Meet the Expert webinar. The website renewal, social media campaigns and webinars are supported by our big-hearted sponsors Pfizer, Bristol Myers Squibb, and Medtronic.

CMANZ has continued to represent the patient voice nationally. At the CSANZ Annual Scientific Meeting, I was pleased to co-chair a session on working with the community to improve cardiovascular care, and to speak at a HCM clinician education day where the patient perspective was strongly valued. Board Member Gordon Thoms and I also attended meetings at Parliament House as part of the BMS Patient and Parliament Summit, discussing proposed changes to PBS processes.

We also acknowledge a significant transition on our Board. We sincerely thank our retiring Board members—Mary Smith, Bronny Stewart, Christine Wilson, Kerry Shaddick and Julian Genn—for their years of dedicated service. Each has played an important role in shaping CMANZ, and we wish them well in their next chapters while hoping to stay connected. We are pleased to welcome our new Board members, Vikki Collins and Dionne Essenstem, as we prepare for another energetic year.


Gordon Thoms and Leigh Bell at the BMS Patient and Parliament Summit

Best wishes for a safe and peaceful festive season.

Leigh

Leigh Bell
President, Cardiomyopathy Australia New Zealand

# Welcome Vikki Collins

Vikki has recently become a member of the CMANZ Board after having been involved in the organisation for many years where she has assisted with coordination of support groups, administration of social media and fundraising. She is passionate about supporting our Cardiomyopathy community, creating awareness and keeping up to date with new information.

Vikki was first diagnosed with Hypertrophic Cardiomyopathy in 2006 at the age of 32 and has been learning about the condition with its highs and lows ever since.

Vikki has a background in administration however recently decided on a career change where she felt compelled to do something more meaningful.

This led her to community aged care where she assists our older community with daily activities and social support gaining great satisfaction from seeing the benefits that this brings to her clients. Vikki enjoys volunteering, time with family and friends, baking sweets and going for rides in the country on the back of her husband's motorcycle.

# Welcome Dionne Essenstem

Dionne joined the CMANZ Board in 2025. Diagnosed later in life with hypertrophic cardiomyopathy (HCM), alongside both of her sons and without any known family history, Dionne's journey with the condition became intensely personal. Just nine months after diagnosis, her eldest son required a heart transplant, fast-tracking their family's experience through the complexities of cardiac care. All three have lived with implantable cardioverter defibrillators (ICDs), which have saved her sons' lives on multiple occasions.

A registered nurse with a career spanning 25 years in paediatric intensive care, Dionne credits her clinical background with helping her family navigate the healthcare system's challenges. She brings this dual perspective, as both clinician and carer, to her advocacy.

Passionate about empowering others with cardiomyopathy, she is committed to improving access, understanding, and support for those living with the condition.

# We're seeking insights from women across Australia!

ARE YOU A WOMAN LIVING WITH CARDIOMYOPATHY?

Were you diagnosed in the past 5 years?

Join our research study to share your journey!

CARDIOMYOPATHY
Australia New Zealand

Have you been diagnosed with cardiomyopathy within the past five years? If so, would you be willing to share your experience in an online round-table discussion with a researcher?

CMANZ is partnering with the Global Heart Hub on an international, patient-led research project exploring women's experiences of being diagnosed with, and living with, cardiomyopathy. Participation involves completing a brief screening questionnaire and joining a 90-minute online round-table conversation with other women and a researcher. Sessions will be scheduled over the next 2–3 months.

A **$300 Visa gift card** will be provided after the session in recognition of your time.

**Register your interest** and complete the screening form **here**

We genuinely appreciate everyone who takes part!

*Note: This study includes all forms of cardiomyopathy except secondary cardiomyopathy and Takotsubo syndrome. If you have any queries, please feel free to get in touch with Leigh via info@cmanz.org.au.*

# Call for Expressions of Interest Consumer Advisors for the Inherited Heart Diseases Laboratory

**Do you have lived experience of Dilated Cardiomyopathy?** The Victor Chang Cardiac Research Institute is seeking expressions of interest from those with lived experience of DCM (patients and family members) for the role of Consumer Advisors for the Inherited Cardiac Diseases Laboratory.
Expressions of interest have been extended!
Read more about the Consumer Advisory Panel here
Print the Expression of Interest Form here

For any questions, and to **submit an EOI form** please email Naomi Arbon:
n.arbon@victorchang.edu.au

Have you joined The CMANZ private Facebook Group yet? If you use Facebook and would like to connect with others in the cardiomyopathy community, you're welcome to join via this link. You can also follow our public Facebook page here.

# Early Gene Therapy Results for Hypertrophic Cardiomyopathy

At this year's American Heart Association (AHA) Scientific Sessions, Tenaya Therapeutics presented early results from its ongoing MyPEAK-1 trial, testing a potential gene therapy called TN-201 for people with hypertrophic cardiomyopathy (HCM) caused by mutations in the MYBPC3 gene.

The investigational therapy uses an adeno-associated viral vector (AAV9) to deliver a healthy copy of the gene into heart muscle cells. Early results from a small group of participants showed the treatment was generally well tolerated, with early signals suggesting possible improvement in some cardiac measures.

Tenaya reported these interim findings via company press releases, conference presentations, and a brief report in the peer-reviewed journal Cardiovascular Research. Longer-term follow-up and larger studies are still needed.

*"These initial results are promising for a patient population that too often live with difficult, even dangerous, symptoms," said Dr Milind Desai, one of the study investigators (Tenaya Therapeutics, AHA 2025 press statement).*

If confirmed in larger studies, this approach could represent a step towards treating HCM at its genetic source rather than managing symptoms alone. More information: ClinicalTrials.gov – MyPEAK-1 (NCT05836259): https://clinicaltrials.gov/study/NCT05836259

# UK Patients Help Define Future Cardiomyopathy Research Priorities

A new project led by Cardiomyopathy UK, in partnership with the James Lind Alliance, has identified that countries Top 10 Research Priorities for Cardiomyopathy.

Through consultation with UK patients, families, carers, and clinicians, the study pinpointed key areas where evidence is lacking. We thought you might be interested in the priorities identified:

- Predicting who will develop symptoms, and when
- Understanding psychological and emotional impacts
- Screening and follow-up for family members at risk
- How lifestyle, stress, and health events trigger disease
- Personalising treatment and improving long-term outcomes

Although this was a UK-based initiative, the findings have international relevance. They highlight the value of involving people with lived experience in setting research direction — an approach CMANZ supports. We will seek to undertake a similar project to gather the voices of Australians and New Zealanders when funding permits.

**Read the full report** here: Cardiomyopathy UK – Future Research Priorities (2024) Future Research Priorities Report

# Heart Healthy Eating: What the Latest Research Shows!

Recent Australian research and guidance continue to highlight the importance of a consistent heart healthy eating pattern for protecting cardiovascular health. According to the National Heart Foundation of Australia, this means a diet rich in wholegrains, fibre, vegetables, fruit, legumes, nuts, and fish, while reducing saturated fats, salt and added sugar.

One current Australian program, led by Dr Kathy Trieu at the University of New South Wales (UNSW), is examining the use of potassium enriched salt substitutes and 'Food is Medicine' prescriptions for people at high cardiovascular risk. These interventions aim to reduce population level sodium intake and improve overall diet quality.

For people living with cardiomyopathy, diet plays a supportive role alongside medical and specialist care. While nutrition cannot reverse or treat the underlying heart muscle condition, healthy eating can help manage blood pressure, cholesterol and inflammation, reducing overall cardiovascular strain.

**Practical tips from the Heart Foundation include:**

- Eating a wide variety of vegetables and fruits every day.
- Choosing wholegrains such as oats, brown rice, and whole-grain bread.
- Replacing saturated fats with healthier fats like olive oil, nuts, seeds, and oily fish.
- Reducing salt by limiting processed foods and avoiding adding salt at the table.
- Planning meals and snacks using mostly fresh, unprocessed foods.

The message is simple: small, consistent choices in what we eat can make a real difference to longterm heart health. A Mediterranean style or plant forward diet pattern aligns with both Australian Heart Foundation advice and global evidence for reducing cardiovascular risk.

Check out great recipe ideas on the Heart Foundation website here

References:
Heart Foundation of Australia – HeartHealthy Eating Pattern: Heart Foundation Healthy Eating
Heart Foundation Research Directory – Strategies to Optimise Sodium and Potassium Intake: Heart Foundation Research Directory

# New Australian Study Shows Genes and Lifestyle Both Matter in TTN Dilated Cardiomyopathy

A new Australian-led study has found that both genes and lifestyle play an important role in how and when people develop Dilated Cardiomyopathy (DCM).

Researchers at the Victor Chang Cardiac Research Institute and international collaborators studied more than 3,000 people across 1,000 families with DCM. They found that those carrying a change in the TTN gene were around 20 times more likely to develop the condition than relatives without the change.

However, the study also showed that genes are not the whole story. Lifestyle factors such as high blood pressure, excess alcohol, high body weight, and other connected health conditions like diabetes or atrial fibrillation also affected when the heart muscle started to weaken.

Men with the TTN change tended to develop DCM earlier than women.

People without additional risk factors tended to develop DCM later in life, suggesting that managing blood pressure, alcohol intake, body weight and other conditions may delay when the disease appears.

“Having a gene change doesn’t mean you will definitely get heart disease,” the researchers said. “It means you can take steps to delay or even prevent it.”

### Why this matters for people and families living with DCM:

- Genetic testing can guide care. Finding a gene change helps doctors know who in the family might need regular heart checks.
- Lifestyle choices still count. Managing blood pressure, limiting alcohol, keeping to a healthy weight, and treating other heart-related conditions can delay or reduce the effects of DCM.
- Family screening saves lives. When one person is diagnosed, it’s worth asking your cardiologist or genetic counsellor whether relatives should also be checked.

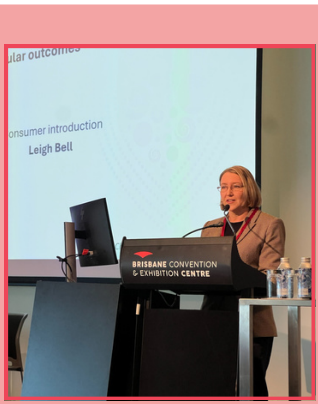
### Questions you might ask your care team:

- Should I have genetic testing for DCM-related genes, such as TTN?
- How often should I or my relatives have heart check-ups or scans?
- What steps can I take to protect my heart if I carry a genetic change?

You can read about the research on the Victor Chang Cardiac Research Institute website here

Lifestyle changes could delay a common inherited heart disease – Scimex (Aug 2025): Scimex - Lifestyle Changes and Heart Disease

Leigh Bell at the HCM Summit



Leigh Bell at the Cardiac Society Meeting

# Global Heart Hub's New Clinical Trial Portal

Global Heart Hub have developed a resource which provides people living with cardiovascular disease – whether newly diagnosed or living long-term with disease, an opportunity for people to have a voice in the future of cardiovascular care and the care of associated conditions.

Global Heart Hub provide information about the different types of cardiovascular health research, how clinical trials work and how people can participate. Further information about this exciting initiative and their clinical trial portal can be found here: Global Heart Hub Clinical Research and Trials.

Additionally, if you are a researcher who would like to have your trial included, please write to Leigh via: info@cmanz.org.au

### CMANZ represented at Global Heart Hub meeting

Our Board Member Donna Harrison, who lives with genetic cardiomyopathy, recently travelled to Spain to join other patient group leaders at the Global Heart Hub's (GHH) Cardiomyopathy Council Meeting. She writes: *"I was thrilled to join the GHH Patient Council Meeting in Madrid in August 2025. Global Heart Hubs' collaborative platform united patients, researchers, and industry to discuss important topics, including highlighting patient experiences as evidence in research and much more!"*

# Get involved: Volunteer with us!

**We need you!** As our community grows, so does our need for passionate volunteers. If you have skills in social media, especially on platforms like Facebook, Instagram, or LinkedIn, or experience in fundraising, we'd love to hear from you. Whether you can contribute just a few hours a month or take on a more active role, your time and talent could make a meaningful impact on the lives of heart patients across Australia and New Zealand.

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

Have questions, feedback, article ideas, or a story to share? We'd love to hear from you, just send us an email and we'll be in touch.

MERRY
Christmas
AND HAPPY NEW YEAR