CARDIOMYOPATHY Australia New Zealand

NEWSLETTER | AUGUST 24

Hello everyone,

Here we are in August already. We missed our July newsletter, but I hope you can understand why when you read about the initiatives we have on the go! We have been busy.

Firstly, as you may have read on our social media, we are very excited to share with you that our charity is undergoing a rebrand! After much consideration and planning, and with the enthusiastic endorsement of members at out June Extraordinary General Meeting, we have refreshed our name and image in order to better reflect the community we serve, and our values. Our new name is Cardiomyopathy Australia New Zealand Ltd. Read more below. We are delighted to also announce the private Facebook Group Cardiomyopathy Australia has returned to its original home within the organisation, and will once again become a private group under our banner (and hence has renamed to Cardiomyopathy Australia New Zealand).

This month, I attended the Cardiac Society of Australia and New Zealand (CSANZ) annual conference, held in Perth (more below). We took the opportunity to hold our first WA support group meeting while I was there, jointly hosted with our local contact person Vikki Collins. It was a small but mighty gathering and personally I found it truly wonderful to connect with others. There was understanding, empathy, and a lot of big laughs. Our next meeting is in South Australia on 22 September, hosted by Bronny Stewart and Kerry Shaddick, and we hope our South Aussie friends can make it. Everyone is welcome! After these two initial test runs, we hope to plan a calendar for each state next year (resources permitting).

I began the month in Perth, and will finish it in London, at a meeting of the Global Heart Hub Cardiomyopathy Council (which I Chair). This affiliation of 27 cardiomyopathy patient organisations from 17 countries, works together to share ideas, best practices, and learn from each other. Adjoining this meeting is a full day session on Amyloidosis Cardiomyopathy, which is a rare form of the disease, where we are discussing how to best support this community. Immediately following is the European Society of Cardiology (ESC) annual scientific conference, which is in London this year, and I'll be attending.

A small but mighty group met in Kings Park, Perth, for our first Cardiomyopathy Cuppa morning tea support group

In this newsletter we also cover our regular series on Gene Therapy, with a closer look at DNA therapy. The Research Spotlight is an incredible development - the implantation of an artificial heart.

August is my transplant anniversary month, and I'm reflecting on my new life just three years post transplant. For me to be able to live this big life, and work on my passion of supporting and advocating for cardiomyopathy patients, is an amazing gift. After being diagnosed with HCM as a child, and a lifetime of intervention (including open heart surgery at 17, 5 ICDs, ablations, cardioversions, 7 years in heart failure, a transplant, and severe complications) it is incredible to be well enough to have these new opportunities and experiences. Thank you my donor, and bless all organ donors and their families.

Kind regards,

Leigh

Leigh Bell
President, Cardiomyopathy Australia New Zealand

Re-branding to Cardiomyopathy Australia New Zealand

We hope you love our new logo as much as we do!

We believe that our new brand will help us connect with even more individuals in need of our services. Our updated logo and messaging will convey our commitment to providing compassionate care and resources to those affected by cardiomyopathy.

We have always welcomed New Zealand members, but we have had feedback that we're difficult to find. We are confident that this rebrand will help us reach new audiences, raise more awareness, and assist more cardiomyopathy patients.

Check out our refreshed website: CMANZ.org.au

Our e-mail has also been updated to reflect the change: info@cmanz.org.au

Please also note we have a **new postal address**: PO Box 2006, Surrey Hills, Vic, 3127, Australia

At the EGM, a resolution to re-structure the organisation was passed, which included an update to our constitution to comply with our charity regulator's requirements (last updated 2012), and modernisation of our membership arrangements to reduce risks to the organisation, and ensure our ongoing viability. If you'd like more information, please get in touch via info@cmanz.org.au.

CARDIOMYOPATHY
Australia New Zealand
The Big-Hearted Community

Facebook Group

We're excited to once again have a **private Facebook Group** as part of our organisation. If you use Facebook and would like to connect with others in the cardiomyopathy community, you're welcome to join via this link. It is a supportive and kind environment where you can ask questions, share about your journey, share a positive story or vent on a bad day to those who understand, or just read the posts of others. (Please answer all questions – this is a group for those with cardiomyopathy and their carers / family only, and we ask the questions to try to keep scammers etc out).

We're grateful to the admins, Bronny Stewart, Vikki Collins, and Sharon Hosking, for their ongoing work in keeping the page operating as a supportive online community, and are very glad to have this group under our banner.

You can also follow our public Facebook page here or by tapping the Facebook icon at the bottom of the page.

Cardiac Society of Australia and New Zealand (CSANZ) conference

At the annual scientific conference in Perth our President Leigh Bell was very honoured to present on behalf of the patient community on the topic of *Obstructive HCM: The Human Impact*. Through reaching out to our HCM community via our Facebook Group, the presentation was able to reflect a variety of views and we are very grateful for those who took the time to contribute. Leigh also had the opportunity to meet with clinicians and representatives from device and pharmaceutical companies.

Image: Leigh Bell (middle) with Dr Antonis Pantozis, Royal Brompton and Harefield Hospital, UK, and Dr Vimal Patel, Fiona Stanley Hospital and Royal Perth Hospital.

Global Heart Hub Key Messages

One of the activities of the Global Heart Hub Cardiomyopathy Council is to develop a set of Key Messages which can be used worldwide by patient organisations. This will help ensure our various awareness raising activities tell a consistent story. There are 6 Key Messages covering a variety of cardiomyopathy facts and we'll share one each newsletter. The first describes the disease:

KEY MESSAGE ONE: Cardiomyopathy is a disease of the heart muscle that can occur at any age and can be passed down genetically.

- Cardiomyopathy is a relatively common, yet little known group of diseases of the heart muscle that tend to progress over time and affect the heart's ability to pump blood through the body and/or cause irregularity of the heart rhythm.
- Cardiomyopathy is a primary disease of the heart muscle that is not caused by heart valve disease or other conditions that increase pressure on the heart.
- It can affect people of all ages and races and is most often passed down genetically.
- Prevalence varies based on type, but overall, cardiomyopathy affects around 1 in every 250 people worldwide.
- Some types of cardiomyopathy are more common than others or more common in certain ethnic groups than in others.
- There are various types of cardiomyopathy, each with unique characteristics and potential impacts on health. The three main types of cardiomyopathy are:
  - **Dilated cardiomyopathy (DCM)** – the most common type of cardiomyopathy; is inherited in up to 40% of casesii; causes the muscle of the heart chambers (ventricles) to become weakened and enlarged.
  - **Hypertrophic cardiomyopathy (HCM)** – the most common inherited cardiomyopathy; characterized by the thickening of the main pumping chamber of the heart (the left ventricle); the left ventricle generally becomes stiffer over time and less capable of taking in or pumping out blood.
  - **Arrhythmogenic cardiomyopathy (ACM) / Arrhythmogenic right ventricular cardiomyopathy (ARVC)** – an inherited form of cardiomyopathy that is characterized by progressive replacement of the heart muscle with scar tissue, causing heart rhythm irregularities (arrhythmias).
- Other less common types of cardiomyopathy include:
  - **Cardiac amyloidosis** – a form of restrictive cardiomyopathy caused by the build-up of amyloid protein deposits in the heart muscle.
  - **Restrictive cardiomyopathy (RCM)** – an uncommon form of cardiomyopathy that is characterized by stiffening of the heart's lower chambers (ventricles).
  - **Peripartum cardiomyopathy (PPCM)** – a rare form of dilated cardiomyopathy that occurs towards the end of pregnancy or in the months following delivery.

Read all about Key Message Two from the Global Heart Hub Cardiomyopathy Council in our next newsletter.

Gene Therapy - DNA

We continue our series on Genetics. Last edition we described the three approaches to gene therapy: DNA Therapy, RNA Therapy, and Cell Therapy. This month we delve into DNA Therapy in more detail.

DNA therapy is the use of DNA that codes for the production of a specific RNA or protein to treat a disorder. To have a therapeutic effect, the DNA must be delivered to the nucleus of a cell, where it can then be used by the cell to affect protein expression. This gene will now live in the nucleus which gives a greater chance of being permanent and is typically only given one time.

- **DNA plasmids** are large, double-stranded circular DNA molecules that code for a therapeutic protein. DNA plasmids can be used for gene addition, vaccination, and cell therapy. A challenge for DNA plasmids is getting them into the cell and then into the nucleus for therapeutic benefit. Clinical trials are ongoing to test the safety and benefit of DNA plasmid therapeutics.
- **Viral vectors** are modified viruses used as vehicles to deliver therapeutic genetic material or specific DNA sequences into a cell. In a viral vector, the viral genes are removed and replaced by a therapeutic DNA sequence encodes genes, RNAs or other substances and packaged inside the shell of a virus. The viral vector is then delivered directly to the body (in-vivo therapy) or to cells (ex-vivo therapy) to deliver the therapeutic genetic material to the nucleus of the cell. In-vivo viral vector therapies are frequently limited to a one-time delivery due to the innate immune response to the virus that usually prevents re-dosing. There are multiple FDA approved viral vector DNA therapies. Read more at The American Society of Gene Therapy (our source).

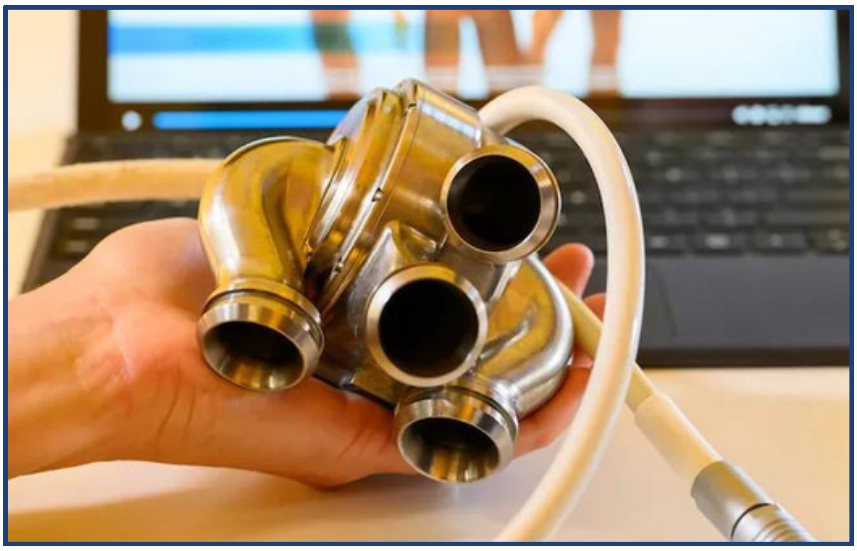
Upcoming Events

Join us at our Big-hearted Lunch for a casual and friendly support group gathering, hosted by long-term members of our team (and board members) Bronny Stewart and Kerry Shaddick. Free event, buy your own lunch. Register via this link or on our website.

Research Spotlight
First BIVACOR artificial heart implanted in a human

The Texas Heart Institute announced in July they had successfully implanted the BiVACOR Total Artificial Heart (TAH) into a human. This represents a momentous step forwards in developing mechanical options for those in end-stage heart failure as a bridge to transplant. Left Ventricula Assist Devices have been available for some time, but these are not suitable for everyone (due to restrictions in a person's anatomy and size). The first-in-human clinical study aims to evaluate the safety and performance of the BiVACOR TAH as a bridge-to-transplant solution for patients in which left ventricular assist device support is not recommended.

BiVACOR's TAH is a titanium-constructed biventricular rotary blood pump with a single moving part that utilizes a magnetically levitated rotor that pumps the blood and replaces both ventricles of a failing heart.



Following this first implantation completed at Baylor St. Luke's Medical Center in the Texas Medical Center, four additional patients are to be enrolled in the study. More information here

Reach out and connect

Thanks for reading! For questions, feedback, article ideas, or story contributions, email info@cmanz.org.au, and we'll be in touch.

You can also **follow us on social media** by tapping the icons at the bottom of the page.

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