

Spring 2022 | Through heart surgery, Dr Victor Chang was able to save hundreds of lives. But he knew that research could save millions.

Saving a young mum – and her loved ones – from cardiac arrest

Six weeks before her wedding, Victoria narrowly survived a cardiac arrest caused by a lethal, inherited heart condition. But a new electrical test could help prevent death from sudden cardiac arrest.

It's now possible thanks to your support, giving families like Victoria's hope.

Young mum Victoria didn't worry too much when she began having fainting spells back in 2021. She put it down to the stresses of a busy career, planning a wedding and taking care of her baby girl Clementine, who was just weeks away from turning one.

Then one evening at home, Victoria suddenly collapsed. Her fiancé Tim raced to the living room to find the love of his life on the floor, unconscious and with no pulse.

She'd had a sudden cardiac arrest.

Luckily Tim knew CPR and fought to keep his beloved fiancé alive for an agonising 16 minutes until the ambulance arrived, and her heart was finally restarted by paramedics.

Victoria was extremely fortunate to survive. She was diagnosed with long QT syndrome, a genetic heart rhythm disorder that can lead to sudden, uncontrollable, and dangerous arrhythmias, which can often end in tragedy.

But thankfully this story has a happy ending. Tim was able to marry the love of his life just six weeks after he brought her back to life. After so nearly losing Victoria, their wedding day was overflowing with love. The couple also celebrated their daughter Clementine's first birthday and have since welcomed another little one, baby Indigo, into the world.

This young family's lives were so nearly very different. Not only that, but Victoria's diagnosis has led to uncovering a hidden family history of heart disease, silently placing her loved ones at terrible risk.

Thanks to medical research, it has now been discovered that both Victoria's mother and her baby daughter Indigo also have the inherited heart condition, long QT syndrome.

This early diagnosis of her loved ones has very possibly saved their lives. Preventative treatments and medication mean they are better protected from the grave risk of sudden cardiac arrest.

In an exciting discovery, researchers at the Victor Chang Cardiac Research Institute have developed a new electrical test that can rapidly screen hundreds of genes to pinpoint the exact mutations that are harmful to the heart for those suffering from potentially deadly inherited heart disorders.

"Being able to identify these dangerous mutations will hopefully prevent people from dying from sudden cardiac arrest and ensure



Victoria almost lost her life to sudden cardiac arrest just six weeks before her wedding, making the day an extra special celebration.

more people are treated for this life-threatening disorder," says lead researcher Professor Jamie Vandenberg.

Both Victoria and her mum now have combined pacemakers and defibrillators implanted in their chests to keep their hearts safe. And, in recognition of her second chance, which she describes as 'miraculous', Victoria has begun organising CPR training for all her friends and family.



If you're one of the generous people who contribute to the Victor Chang Cardiac Research Institute, thank you. The next stage of this research is to determine which genetic variants are dangerous. The findings will then be uploaded to a giant genetic database that will be accessible to clinicians the world over, with the hope of saving as many lives as possible.



20,000
Australians suffer a
cardiac arrest each year



Heart disease kills
3 times more women
than breast cancer

1 IN 100 babies
are born with congenital
heart disease every year



RESEARCHER PROFILE



Dr Lee Nedkoff –
investigating the
health of the nation



Who's at risk? Dr Lee Nedkoff wants to know

Dr Lee Nedkoff, the new head of the Cardiology Population Health Laboratory in Western Australia, believes passionately that using health data can reveal who is most at risk of developing heart disease in the community.

As an epidemiologist who studies the pattern and causes of diseases within the population, Dr Nedkoff provides valuable insights into the true burden of heart disease on our community.

Dr Nedkoff first trained as a physiotherapist and mostly worked in hospitals. It wasn't until after the birth of her first child that she decided to do a Masters degree in Public Health and discovered epidemiology.

"I loved epidemiology from the start. I enjoy the challenge of turning large amounts of data into statistics and evidence that helps increase our understanding of a disease. Whether that's aimed at governments and policy, clinicians or the public," says Dr Nedkoff.

To pull together information from a variety of sources and paint a picture of the health of a nation or a specific population, requires patience and a methodical approach.

Dr Nedkoff's insights are a vital new addition to the research taking place at the Institute.

Knowing the causes of cardiovascular disease and identifying which groups of people are at most risk, means new strategies to beat heart disease can be developed. These strategies can include public health campaigns to prevent people developing heart disease and research programs to deliver treatments for people at risk of dying from heart attacks.

Outside of her work at the Institute Dr Nedkoff is mum to three teenagers, balancing a busy household in Perth. When she gets a rare moment to herself, she turns to reading, particularly the classics, or unwinds with a yoga session or a long walk.



Your support enables scientists like Dr Nedkoff to contribute to our increasing knowledge of heart disease across Australia and its impact on our community.



Welcome and thank you

Thanks to the ongoing support of our generous donors like you, the Institute continues to make progress on the causes and treatments for heart disease.

The response to our recent tax appeal has been outstanding and I'd like to thank all those who so generously gave to revolutionary funnel web spider research. We look forward to updating you on the developments of this research as they happen.

All donations, large or small, are important and help solve the mysteries of heart disease. I hope you enjoy reading about how you contribute to this in the latest edition of The Beat.

One exciting project is a new genetic test developed by Professor Jamie Vandenberg and his team that could prevent many deaths by identifying people at risk of sudden cardiac arrest.

And the dream of an artificial heart may soon become a reality. Professor Chris Hayward from the Institute is working with the developers of the mechanical heart to commence clinical trials, potentially even this year.

We often receive enquiries from supporters who would like to know more about how to join clinical trials. If you are interested, there's an initiative I am happy to share with you, check out the Join Us register run by our partners at The George Institute and UNSW Sydney.

Thank you again for your generous support. I do hope you enjoy reading more about what your gifts help achieve.

Warm regards,

PROFESSOR
JASON KOVACIC
EXECUTIVE DIRECTOR



♀ 24 women die from heart disease every day



Heart disease kills more people than any other single disease



Every minute someone is admitted to hospital for cardiovascular disease

INNOVATION & DISCOVERY

You are helping pump new life into heart transplant patients

As a supporter of the Victor Chang Cardiac Research Institute, you are helping us find new ways to care for patients in end stage heart failure.

For decades, scientists have been trying to build a long-lasting replacement for the human heart. It's considered a Holy Grail of modern medicine and could save tens of thousands of lives every year.

Thanks to generous supporters like you, what was once a dream is now getting closer to reality.

A MECHANICAL HEART

Professor Chris Hayward and his team at the Victor Chang Cardiac Research Institute are collaborating with Australian biotech company BIVACOR. The company has been developing an artificial heart for the past two decades.

So how does an artificial heart work?

The mechanical device is designed to entirely replace the human heart when both the right and left ventricles are failing. It's implanted and then connected to an external power source to fully restore normal blood flow around the body.

For patients whose hearts have totally failed, the artificial heart offers a lifeline. Once implanted it can restore a person's heart function while they wait for a heart transplant. (Although the device is able to actually provide more than 10 years of support!)

The technology has been thoroughly tested and now the mechanical heart is ready to be trialled in patients.

SAFETY CHECKS COMMENCE IN CLINICAL TRIALS

Professor Chris Hayward is now working with his collaborators to prepare for clinical trials which are planned for late 2022/early 2023.

"The next trial stage is to make sure it's as safe and reliable as possible," Professor Hayward says.

This stage includes placing the device in the chests of heart transplant patients to learn about its fit and placement.

A MAJOR MEDICAL BREAKTHROUGH

Professor Hayward is excited to be on the cusp of such a major medical breakthrough.



"This really is the Holy Grail of transplant medicine, and we're happy to be involved at the pointy end because it hasn't happened overnight, there's been a lot of work to get to this stage," says Professor Hayward.



Professor Chris Hayward and Dr Sam Emmanuel in the lab with the total artificial heart.



A new artificial heart could give fresh hope to people waiting on heart transplants.



One Heart

There are various ways you can support vital cardiac research. You can choose to become a **One Heart Supporter** by making a regular monthly gift, hold a fundraising event, organise donations in lieu of presents or even include a gift to the Victor Chang Cardiac Research Institute in your Will. To find out more please visit victorchang.edu.au/support-us or phone 1300 842 867.

If you would like to discuss including a gift in your Will, please call Bequest Manager Samantha Burns on (02) 9295 8753 for a confidential conversation.



Estimated **1 IN 200**
people have hypertrophic
cardiomyopathy

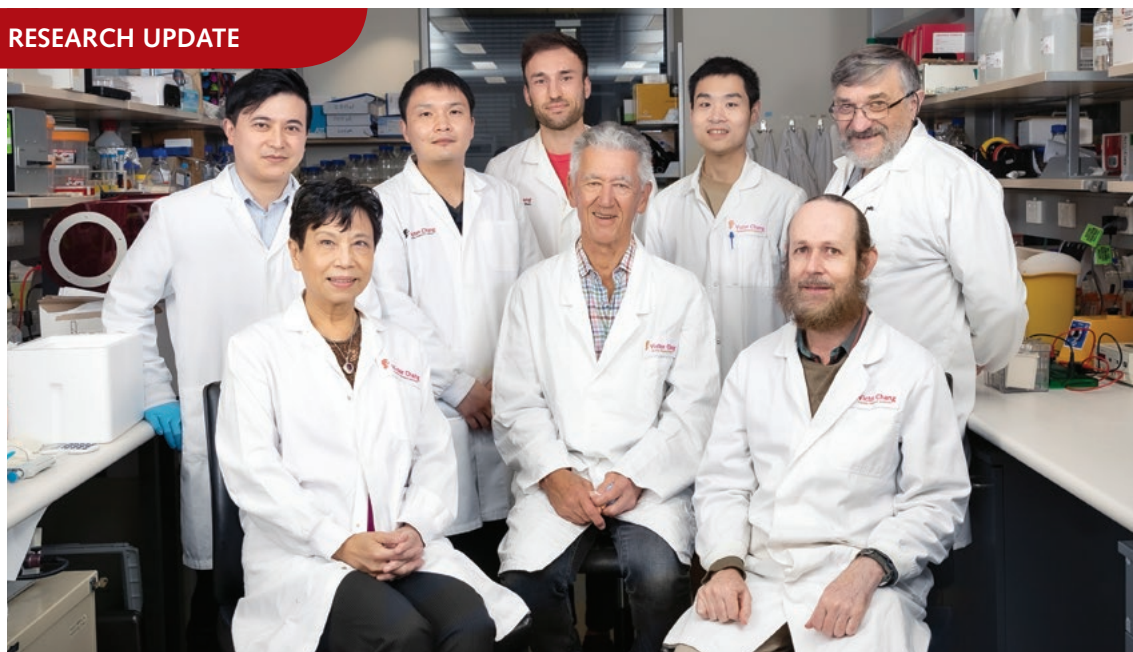
40%

more men than women die
from cardiovascular disease



Atherosclerosis is the **number 1**
cause of cardiovascular disease

RESEARCH UPDATE



With your help,
Professor Boris
Martinac and his
team have made a
vital breakthrough
that could prevent
thickening of the
heart muscle.



Discovery makes a new preventative treatment for cardiac hypertrophy possible

In an exciting new breakthrough – and thanks in part to supporters like you – our scientists have now discovered one of the key causes of cardiac hypertrophy, paving the way for a potential new preventative treatment.

WHAT IS CARDIAC HYPERTROPHY?

Cardiac hypertrophy is caused by many common conditions including abnormally high blood pressure and narrowing of one of the heart valves (aortic stenosis). Genetic factors are also likely to be involved.

It affects around one in every 500 Australians, causing the wall of the main pumping chamber (left ventricle) to thicken.

Over time this thickening can cause abnormal heart rhythms and lead to heart failure. For patients who are suffering heart failure, their chance for survival drops to less than 50% after five years.



“Cardiac hypertrophy is a key risk factor for premature cardiac death and is a major cause of heart failure,” said Professor Boris Martinac, the lead author of the research.

AN EXCITING DISCOVERY

After almost 15 years of research, scientists at the Institute have finally been able to pinpoint a key reason why the heart muscle wall thickens. Our team has identified the specific molecules and signalling pathways that cause this process to take place.

This is a huge breakthrough that could have enormous implications for future treatments.

This discovery means there is now potential to develop a therapy that will stop these molecules from activating. This could prevent the heart muscle from thickening in the first place and for those already suffering the effects of the process, it could halt any further damage.

Currently, there are limited therapeutic options for severe hypertrophy. The traditional approaches include lowering the patients' blood pressure or replacing a stenotic aortic valve – neither of which fully reverse the damage caused by hypertrophy.

But thanks to this breakthrough, there's now more hope. In a further exciting development, the team is also investigating whether the new approach to preventing cardiac hypertrophy could also help with the recovery of heart attack patients.

Thanks to you and others like you, people living with cardiac hypertrophy have hope of a treatment that may prevent them developing heart failure. This could be a truly life-saving discovery. Thank you.



This preventative treatment could make a huge inroad into reducing the number of people affected by heart disease in Australia and hopefully save many lives in the future.”
Dr Jane Yu, Researcher

Cardiac arrest survivor completes his first half marathon



One year since we first shared his story, cardiac arrest survivor, Jesse, is fighting fit and kicking goals.

Less than two years ago, Jesse dropped dead playing indoor football. Now he's achieving incredible things.

Perhaps you remember Jesse, the young man whose story we shared exactly one year ago?

In January 2021, Jesse suddenly dropped dead playing futsal with his friends. He had suffered a sudden cardiac arrest.

The defibrillator at the stadium couldn't be found that day, but the speedy actions of Todd, an off-duty policeman who quickly started CPR, without doubt saved Jesse's life.

"I'm one of the lucky ones. Not many get as lucky as me to live a normal life after a sudden cardiac arrest. I'm doing really well and looking forward to a long and healthy life ahead," Jesse reflects.

Jesse was fitted with a defibrillator which will regulate his heart rhythm to ensure he doesn't suffer another cardiac arrest.

"It acts as a guardian angel in case my heart ever goes into that life-threatening rhythm that triggered my cardiac arrest again, the defib will kick in and that is a huge relief for me."

At first Jesse, who always led an active lifestyle, found it a little daunting to get back into sport.

"To be honest I was a bit nervous to get back into exercising again and I felt a little fragile for a while. But with each passing day, it becomes more of a memory."

Now he's well and truly back on his feet and incredibly he's just completed a 23km marathon along The Great Ocean Road in Victoria!

There's no stopping Jesse and we can't wait to hear what challenge he tackles next.

NEWS

New lab to open in WA tackling the 'silent killer'

With the support of Ben Beale's family, a new laboratory is opening in Western Australia. Thanks to the generosity of the 'Group of Hearts'.

In 2017 Ben Beale, a loving father of five, died suddenly at 47 years old from a heart attack.

He was completely unaware he had atherosclerosis, the hardening and narrowing of the arteries in the heart. It's known as the 'silent' killer because there are often no apparent symptoms.

After his tragic death, Ben's family dedicated themselves to preventing others enduring the same heartbreak they went through. They have joined forces with the Victor Chang Cardiac Research Institute to establish a new laboratory in Perth to accelerate research into cardiovascular disease. Ben's family hopes this research will lead to treatments for atherosclerosis, the leading cause of heart attacks.

"I wish Ben was still with us, but this will be an incredible and lasting tribute to the best father in the world and a caring and generous husband who was loved by so many people," said Ben's wife Sarah.

Professor Livia Hool, head of the Institute's WA division says "The aim is to stop atherosclerosis from occurring in the first place. That would be transformative in the treatment of heart disease."

Scheduled for August 2022 the official opening of the Ben Beale Laboratory will be held to celebrate the generosity of the 'Group of Hearts' who has raised over \$1.8million



Ben Beale's five children tragically lost their dad to a sudden heart attack when he was only 47.



The Ben Beale Laboratory in Cardiovascular Research at the University of Western Australia will be a first for the Institute as we expand our national footprint and pursue bold and impactful research projects around the country.

JOIN US

Would you like to do even more to support medical research?

You can! By signing up to the Join Us register – a secure program that matches volunteers with research studies.

In 2020, our colleagues at the global medical research centre, The George Institute, along with the UNSW Sydney, established the Join Us register. The purpose is to link people

who would like to participate in clinical trials with researchers doing studies they are eligible for.

Clinical trials are essential for finding new treatments for diseases, as well as new ways to detect, diagnose, and prevent illnesses. Importantly, clinical trials can show researchers whether or not particular drugs

are effective and safe for treating people who are suffering from life threatening and chronic diseases.



If you would like to register to participate in life-saving health and medical research, head to joinus.org.au

OPEN YOUR HEART



"Heart research saved my life", says Julie, who has included a gift in her Will to the Victor Chang Cardiac Research Institute.

"Your gift to heart research can live on" – Julie, NSW, Bequestor

Have you considered including a gift in your Will to the Victor Chang Cardiac Research Institute?

If you or someone you love has heart disease, you'll know how important it is to find the causes and treatments that could help save lives.

Julie was diagnosed with congenital heart disease when she was just a baby. She has undergone multiple open-heart surgeries, twice when she was only a little girl. Since then, she has suffered several strokes and a cardiac arrest as well.

"I couldn't have come this far in life without the dedicated researchers and brilliant medical professionals I have encountered over several decades. The advances made in medical technology have been absolutely life changing for me."

For Julie, who knows she may one day need a heart transplant, the Institute's work with artificial hearts fills her with hope.

Julie has generously included a gift in her Will to the Victor Chang Cardiac Research Institute.

Her gift will provide funding for innovative ideas that could lead to world first treatments, speed up lifesaving discoveries or train the next generation of researchers. It's a legacy that will truly impact many lives and help those suffering from cardiovascular disease.

If you would like to consider including a gift in your Will, please contact Samantha Burns, Bequest Manager, for a confidential conversation by calling (02) 9295 8753 or by sending an email to bequests@victorchang.edu.au

APPEAL UPDATE

You did it! Overwhelming support for funnel web spider research

Our pioneering research involving the venom from one of the world's deadliest spiders has received enormous encouragement from the community. A protein derived from the spider's venom has the potential to help repair damage to the heart after a heart attack and improve the viability of hearts for transplant.

We couldn't do this without the generous donors who gave to our tax appeal to ensure this vital research continues.

Your generosity has helped raise a truly incredible \$359,648.80, surpassing our target of \$303,000 and bringing us closer to first-in-human trials.



From everyone at the Victor Chang Cardiac Research Institute a huge thank you!