

Spring 2021 Through heart surgery, Dr Victor Chang was able to save hundreds of lives. But he knew that research could save millions.

### "I had no warning whatsoever."

Nothing could have prevented 24-year-old Jesse from suffering a near-fatal sudden cardiac arrest.

### But your support could mean a very different future for those at risk.

Jesse knows he is one of the lucky ones. When he suffered a sudden cardiac arrest playing indoor soccer early this year, an off-duty police officer began CPR immediately. Without his quick action, Jesse would not have left the stadium alive.

"At hospital, I was put in an induced coma and doctors told my parents all we could do for now was wait," says Jesse. "The days to follow were the most traumatic of their lives."

Every year, 20,000 Australians suffer sudden cardiac arrest. Only one in 10 survive. Despite these sobering statistics, the cause of many of these deaths remains a mystery even when an array of tests and autopsies are performed.

At the Victor Chang Cardiac Research Institute, we're on a mission to stop lives being lost to sudden cardiac death through groundbreaking research you help fund.

Our scientists are uncovering the genetic causes of sudden cardiac arrest that could save lives and prevent heartbreak for families.

Professor Jamie Vandenberg's dream is to create a genetic database that could soon prevent people like Jesse from being struck down without any warning.

This database will store the genetic mutations that are known to cause sudden cardiac arrest and help identify those most at risk, ensuring they receive preventative treatment.

This will also allow clinicians and researchers to learn far more about these deadly genetic mutations and help us to develop strategies to prevent sudden cardiac arrest.



"This genetic database could substantially reduce the number of cardiac arrests caused by genetic disorders," says Prof Vandenberg. "It's something I'm absolutely determined to achieve to help these families."

Jesse isn't back on the soccer field yet, but he's recovering well. He has a small battery powered defibrillator (ICD) implanted in his chest to shock his heart into life if it stops again. He's also undergoing testing see if a genetic mutation was the cause of



Jesse is making the most of each day with those he loves. His great hope is that research could stop others dying of sudden cardiac arrest like he almost did.

his unexplained cardiac arrest. These answers could prevent the heartache of another family member suffering a cardiac arrest – possibly even Jesse's own child one day.

"I've realised it wasn't just me who got hurt that day," says Jesse. "The whole network of people I'm connected to felt the trauma of almost losing me. Without research, we are just going to keep losing so many people to cardiac arrest. It's a shocking future for anyone to lose a family member this way."

Thank you for making Prof Vandenberg's research possible. You are helping us work towards a future where loved ones are not lost without warning to sudden cardiac arrest.

- Why are the heart conditions that cause sudden cardiac arrest so hard to detect with standard tests?
  - "People who have these gene mutations show no signs or symptoms they are at risk," explains Prof Vandenberg. "Even after they have a cardiac arrest and die, you could examine their heart in the most minute detail and find nothing wrong. That's why it's so important to understand the genetic mutations causing cardiac arrests in seemingly healthy people."



coronary heart disease

of Australians have at least one risk factor heart disease

#### **RESEARCHER PROFILE**



Muthiah, whose clinical research is focused on helping those patients with end-stage heart

### A passion to save the lives of patients at death's door

Name: Dr Kavitha Muthiah

**Clinical Faculty Member** 

#### Making a difference to people suffering end stage heart failure is what inspires our newest Clinical Faculty Member Dr Kavitha Muthiah.

"In 2010 as part of my training to be a cardiologist I fell in love with the sub-specialty of advanced heart failure and transplant," she says. "It's not only the science: I love looking after these patients."

A patient in end stage heart failure is often being kept alive through an artificial heart pump, while they wait for a heart transplant. "They are often knocking on death's door before they get the pump implanted," she says.

Dr Muthiah has seen firsthand the awful side effects that can be caused by this artificial pump. Blood clots, infections, device malfunctions and bleeding are just some of the risks.

With your help, Dr Muthiah hopes she can understand more about how the body responds to the artificial pump, so patients can receive a personalised medicine approach that's best for them.

> "I am passionate about advanced heart failure and transplant, because you can make a huge difference, saving lives with this technology, and with transplant," she says. "It's such a rewarding experience to see them on the other side.

"I'm so excited and feel privileged to work for the Victor Chang Cardiac Research Institute; a world-class centre of excellence."

#### You are accelerating discoveries, thank you

Recently, we've seen COVID-19 vaccines developed at lightning-speed. The future of science is here, and in this edition of *The Beat*, one of our leading scientists, Professor Jamie Vandenberg, shares how genetic research is also moving at a pace we never thought possible. Every day we are learning more and more about sudden cardiac arrest, and we intend to arm clinicians with vital genetic information that could prevent needless loss of life. That's extraordinary and it's thanks to your support.

I hope you enjoy catching up with Jayden, who you may remember from a past edition. One day Jayden was in the cricket nets with his son Henry, the next day he was in a coma with heart failure. Today, Jayden is living his life to the full, thanks to research you made possible. His incredible family story demonstrates how far we have come in just a few short years and inspires us all to keep working to solve the unsolved.

I also want you to meet one of our newest members to the Institute, who has a passion for helping the people who are literally on death's door. Dr Kavitha Muthiah is determined to discover new ways to keep patients awaiting heart transplant healthier - but she can't do it without you.

Thank you for putting your trust in the Victor Chang Cardiac Research Institute, Australia's home of heart research. It's never been a more exciting time to work in heart research. Your generosity is saving lives every day.

Warmest regards



PROFESSOR JASON KOVACIC EXECUTIVE DIRECTOR



**100 Australians** are waiting for a heart transplant at any one point **30** babies undergo heart surgery in Australia every week



20,000 Australians suffer cardiac arrest every year

**INNOVATION & DISCOVERY** 

# World-first discovery could reduce heart attacks in women

It's widely known that women have different heart attack symptoms and risk factors to men.

But, it's always been a mystery as to what these differences are on a genetic level – until now.

Our scientists have made an exciting breakthrough that could lead to new and more effective treatments tailored to female heart attack patients.

In an effort spanning Australia, the USA and Europe, Professor Jason Kovacic, and his colleagues mapped the genetic profile of hundreds of men and women at risk of coronary heart disease.

The team found men who are at risk of having a heart attack show changes in the wall of their blood vessels that suggests genetic changes in their immune system.

But for women, the key genetic drivers of this process are instead the most common cells in the walls of their arteries – known as smooth muscle cells.

It has allowed scientists for the first time to witness and finally understand some of the core mechanisms of heart disease, which takes the lives of three times as many women as breast cancer.

"It's a pretty rare moment when you get profound insights like this," says Prof Kovacic. "This has blown the doors open and created a whole new way of understanding why coronary disease is different in women and men.

"The results will lead the way forward to potentially develop new medical therapies, tailored to women – and men too. We're really excited about where this will progress."

In Australia each year around 50,000 women have a heart attack or other cardiac emergency. It's only with your support that the Institute can find new ways to diagnose, prevent and treat cardiac disease. Thank you!



Thanks to your generous support, research by Prof Jason Kovacic and a global team could pave the way for better treatments for women who suffer heart attacks.

"This has blown the doors open and created a whole new way of understanding why coronary disease is different in women and men."

Prof Jason Kovacic

#### SUPPORTER SURVEY



# The impact of your support is felt every day and your feedback is really valuable. That's why we are inviting you to complete your **enclosed Supporter Survey**.

By filling out your Supporter Survey, and returning it in the enclosed reply-paid envelope, you will help us learn more about the areas of our work you're interested in, so we can communicate better with you. We look forward to hearing your thoughts!



Heart disease kills more people than any other single disease



Heart disease kills 3 times more women than breast cancer Cardiovascular disease affects 2 out of 3 families

**RESEARCH UPDATE** 

## Imagine a heart that could heal itself

It sounds like sci-fi, but one day we may be able to turn on a secret switch that will help our hearts self-repair after a heart attack.

Scientists at the Victor Chang Cardiac Research Institute have been studying an incredible little sea-dweller called a zebrafish which can actually perform this amazing feat.

In a world-first study they have discovered it's all down to a critical gene that it is hoped could also help heal human hearts one day.

Dr Kazu Kikuchi, who led the research, discovered the gene known as Klf1 plays a vital role after a zebrafish has a heart attack. It turns on cells, allowing them to divide and multiply, which then regenerates and heals the zebrafish's damaged heart.



"Our research has identified a secret switch that kicks in when needed and turns off when the heart is fully healed," says Dr Kikuchi. "In humans, where damaged and scarred heart muscle cannot replace itself, this could be a game-changer.

"With these tiny little fish sharing over 70% of human genes, this really has the potential to save many, many lives and lead to new drug developments."

After eight years at the Institute, Dr Kikuchi has returned to his homeland Japan. From there, he will continue to seek clues on how this genetic switch could lead to regeneration in human hearts.



Dr Kazu Kikuchi believes this genetic breakthrough could be a "gamechanger" in helping us understand how damaged human hearts could one day heal themselves.



The tiny Zebrafish has a remarkable ability to self-repair it's heart muscle.



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 Deborah Smith on 0415 967 267 or Samantha Burns on (02) 9295 8753. They would be delighted to have a confidential conversation with you.

# "I'm living breathing proof of what your donations can achieve."

You may remember Jayden, whose story we shared in The Beat last year. It's now two and half years since he underwent a heart transplant which led to a new outlook on life and, as he describes himself, 'Jayden 2.0.'



In just one generation, research made possible by supporters like you, has given Jayden (pictured, with his son Henry) a radically different prognosis compared to his mother, who also suffered heart failure.

Jayden was just 46 years old when the common flu virus attacked his heart, causing it to become so inflamed he was left in end-stage heart failure.

It was history repeating itself. Twenty years earlier Jayden's mum died from the very same condition. Now his son Henry was facing the very real possibility of losing his dad too.

But this father and child had a different outcome thanks to research conducted at the Victor Chang Cardiac Research Institute. The 'heart-in-a box' that was developed alongside a unique preservation solution at the Institute has revolutionised heart transplantation.

This world-first invention has dramatically extended the amount of time a donor transplant heart can spend in transit, from four to 14 hours, meaning there are now a third more hearts available for people like Jayden.

After almost dying, the result, he chuckles, is the new and improved "*Jayden 2.0.*" He's focusing on being the best dad in the world to son Henry, raising funds for the Institute and being an advocate for organ donation.

It's a purpose he knows would make his mum proud. "She agreed to every bit of testing and gave her heart to research."

And it's the power of research that has inspired Jayden and Henry to undergo genetic testing. "So much has been achieved through research in such a short time, what was not available to my mum is now available to Henry and I."

"What the Institute is doing for people like me is just incredible and its world leading" he says. "All of these breakthroughs start with research, the whole world is going to benefit – but we get it first here in Australia."

And Jayden has something important to say to you too:

"The Institute's supporters are as important as the organ donors who provide heart donations to people like me," he says. "I will never be able to repay what has been given to me."

"Thank you are the two words I have for people like you. I am living breathing proof of what your donations can achieve!"

#### **OPEN YOUR HEART**

The entire team here at the Victor Chang Cardiac Research Institute are immensely grateful for each and every gift we receive from our supporters, our work would simply not be possible without you.

Cardiovascular disease impacts 4.2 million Australians every year. Our scientists are working tirelessly to change that for the better and love to read your words of encouragement. Here are just some of the kind messages we have received about why you so generously choose to support us, **thank you!** 

### Seeing great changes

"After 40 years of nursing, I witnessed many challenges for young and old. Now retired for 25 years and with very limited funds. I like to see the changes taking place in diagnosis and treatment. My mother had bypass surgery about 40 years ago. She is now 102. Thank you. I wish you continued success."

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#### Solving the unsolved

"My father, mother and brother have all died from heart problems. I am now nursing an aortic valve problem. I feel indebted to all the diligent researchers who have not given up in finally meeting with success on 'solving the unsolved'. My sincere thanks."

# Saving lives

"There is nothing more important than trying to save a human life."

### For the people I love

"I realise that someone who I love very much could die suddenly so I would like to help as much as I can."

## The importance of research

"Heart problems affect many young children and research is so important to give them a normal life."

### We welcome back the Heart Health Check Booth with 1,140 NSW residents tested so far

Our nurses are thrilled to be providing free heart checks in the community once more.

#### Importantly, more than two in five people tested so far had results outside the healthy range and were recommended to follow up with their GP.

It's reported that an estimated 100,000 Australians have gone without regular medical advice since the start of the global COVID-19 pandemic, putting lives at risk.

"Coronary heart disease is killing more Australians than any other single disease. It is largely preventable. Now more than ever there is a need for Australians to get checked." – Jayne Baric, Heart Health Check Manager.



Our nurses are committed to offering potentially life-saving heart health advice in less time than it takes to drink a cup of coffee.

# How a 10-minute check-up can save lives

Since 2010 80,000 Australians have been tested at the Heart Health Check Booth.

- One in 12 people have high blood pressure
- One in three people have high cholesterol
- One in 13 people have high blood sugar.

You can find out if our Heart Health Tour is coming to your town by visiting

#### victorchang.edu.au/heart-tour

If you have concerns about your heart health, book an appointment with your GP today.

#### UPCOMING EVENTS

### The Bay Soirée

#### Save the date: Friday 15 October 2021.

The Victor Chang Cardiac Research Institute's signature fundraising event The Bay Soiree returns for its seventh year.

In March 2020, The Bay Soiree raised an incredible \$125,000 in just one evening towards vital research, helping the Institute to find better treatments and cures for heart disease.

We look forward to welcoming you to another unforgettable night overlooking Sydney Harbour. Held in partnership with Watsons Bay Hotel, enjoy delicious canapes and bespoke cocktails barefoot on the beach, while watching the sun set over Watsons Bay.

Tickets now on sale. Email: events@victorchang.edu.au



Enjoy a night to remember at the 2021 Bay Soiree and help fund much-needed cures for heart disease.

# Women Against Heart Disease Lunch

### Visit victorchang.edu.au/events/womens-lunch for event details.

This annual event is dedicated to raising vital funds for women and heart disease, the leading cause of death in women.

On the day, the Institute's Executive Director Professor Jason Kovacic will share an exciting breakthrough that could reduce heart attacks in women. Special guest, country singer star, Victoria McGee, will also be speaking at the event.

In light of the ongoing COVID-19 developments, the Women's Lunch has been postponed until later this year. We remain excited to host the 2021 event and keep an eye on our website for when a confirmed date is announced.



This special event raises vital funds for research into heart disease, which impacts more than half a million women in Australia.