



Victor Chang
Cardiac Research Institute

THE BEAT

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



LIFE ON THE TRANSPLANT LIST

As 18-year-old Joel Seeto discovered, heart disease can affect anyone – male, female, old or young.

Four years ago, Joel Seeto felt like any other fit, healthy teenage boy. When he wasn't at school he was playing football, surfing or socialising.

He never would have thought that at just 18 years old he'd find himself on the waiting list for a heart transplant.

Joel was just 14 when he was diagnosed with hypertrophic cardiomyopathy (HCM) – a genetic heart condition that causes thickening of the heart walls, making it increasingly difficult for the heart to pump blood.

Over the past year Joel's condition has deteriorated and it was just in the past month that he was officially added to the heart transplant list. "Back when I first got diagnosed I could go a day without thinking about it," says Joel. "But ever since I was told to speak to the transplant team it's definitely something I think about every day...At that point I freaked out a bit."

HCM affects around one in every 500 people and is the leading cause of sudden cardiac death in

children and young people. Most of us have heard stories of a sports star or athlete suddenly dying of heart failure, seemingly out of nowhere. In most instances this is caused by HCM. Unfortunately HCM does not always have obvious symptoms so it can go undetected for years. For some people, the first symptom will be death.

Once a keen football player, Joel recognises how lucky he was to discover he is living with HCM when he did. "Lots of people have the same condition as me but they don't have any symptoms at all – even professional athletes," says Joel. "I'm pretty lucky that nothing ever happened to me while I was playing."

Joel is enthusiastic about research taking place at the Victor Chang Cardiac Research Institute that has the potential to prevent future generations suffering from HCM. Researchers at the Institute are studying a gene mutation that is known to cause HCM and are exploring switching this gene off at certain times during the heart's development. This has led to a breakthrough that suggests the abnormal heart muscle thickening of HCM can only be prevented if the mutated gene is turned off before adolescence. If it isn't, the thickening will persist, so treatment may need to be started much earlier than it is currently, and certainly before the adolescent growth spurt. This discovery has the potential to unlock the development of preventatives – and even one day cures – for hypertrophic cardiomyopathy.

While HCM is usually an inherited disease, there was no history of HCM in any other members of Joel's family, which further emphasises that heart disease does not discriminate. It can affect anyone, regardless of age, gender, physical fitness, or even family history.

Joel hopes that by speaking out and telling his story, he can encourage people to get tested and help prevent deaths caused by undetected heart conditions. He is passionate about raising awareness because, as Joel explains, "heart disease is the number one killer, but lots of the time it can be prevented."

While Joel admits that the past few years have been tough – giving up playing sport and coming to terms with his condition – he looks towards his future, and the reality of needing a heart transplant, with positivity and pragmatism. "I've thought about it and in the long run it's actually a good thing, because after I recover I can go back to surfing and playing touch footy and stuff...I just want to get on with it and live a normal life."



Heart problems can affect anyone – your friends, your family – you never know.



1/500

people are affected by HCM

9/10

Australians have at least one risk factor for cardiovascular disease

1/5

Australians, or 3.72 million people, are affected by heart disease

1st



The heart is the first organ to form. You don't need a brain to develop a heart!

INNOVATION & DISCOVERY



RESEARCH: ON THE BRINK OF DISCOVERY



PREVENTING THE LEADING CAUSE OF SUDDEN CARDIAC DEATH IN YOUNG PEOPLE.

36,000

Australians are affected by hypertrophic cardiomyopathy.

PHOTO: Xiaohui Xiao, Senior Post Doctoral Fellow and member of Prof. Feneley's lab (inset) conducting an experiment at the Victor Chang Cardiac Research Institute.

There's nothing more tragic than the sudden, unexpected death of someone in the prime of their life. A genetic condition called hypertrophic cardiomyopathy (HCM) is the leading cause of sudden cardiac death in children and young adults. Around 36,000 Australians are affected by HCM and 360 people die from the disease each year. Researchers at the Victor Chang Cardiac Research Institute are gaining new insights into HCM and are getting closer to discovering treatments for this potentially fatal disease.

Hypertrophic cardiomyopathy causes thickening of the heart muscle wall, which can block blood flow and make it increasingly difficult for the heart to pump, or can cause electrical disturbances that result in sudden death. The cause is generally a faulty gene, passed down through families. Although the gene is present from birth, the symptoms and signs of HCM usually appear later in life, during adolescence or early adulthood. Symptoms can include chest pain, dizziness, shortness of breath or fainting. However, some people do not experience any symptoms at all, meaning that HCM can go untreated, leading to sudden cardiac death, especially in young athletes.

While HCM is a genetically determined disease, research currently underway at the Victor Chang Cardiac Research Institute, headed by Professor Michael Feneley AM (pictured above with his team), suggests that it may be possible to prevent the development of hypertrophic cardiomyopathy by intervening in the heart's growth during adolescence.

The research team have been testing a gene mutation shown to cause HCM by attempting to "switch off" this gene at various times. In a breakthrough discovery, the researchers found that switching the gene off after adolescence had no effect. The faulty gene appears to impact the heart during the period from birth to adolescence. This finding has transformed the way we think about what was previously considered an adult-onset disease, and has shown for the first time that the heart's development in the period before adulthood is crucial in determining whether a person will develop HCM in later life.

If our researchers can gain a deeper understanding of how and when HCM manifests, the hope is that one day it will be possible to prevent people suffering the devastation of this potentially deadly disease.



It is estimated that more than 340,000 Australians have had a heart attack at some time in their lives



10,000

The average number of lives claimed by heart attacks a year

RESEARCHER PROFILE



UNDERSTANDING THE 'SILENT KILLER'

Name: **Prof. Roland Stocker**

Faculty: **Vascular Biology**

By challenging dogma and thinking outside the box, Professor Roland Stocker is on the path to understanding atherosclerosis – described as the 'silent killer'.

Atherosclerosis is the biggest cause of heart attack, stroke and death in Australia. There's a reason this deadly disease is considered a 'silent killer'. Caused by an undetected build-up of fatty deposits, cholesterol and plaque on the inside of the arteries, atherosclerosis can lead to life-threatening blockages in the arteries, putting blood flow at risk as it slowly destroys the heart.

In 2012, Professor Stocker established the Victor Chang Cardiac Research Institute's new Vascular Biology Division with the aim of discovering what causes atherosclerosis, and how it can be stopped. Professor Stocker and his team are currently investigating the relationship between a particular molecule called Coenzyme Q10 (CoQ10) and atherosclerosis. CoQ10 is a substance that is naturally found in every cell of the body, but its levels are highest in the heart. As we age, CoQ10 levels within the heart decrease. Professor Stocker believes heart failure may be partly due to this deficiency in CoQ10.

Why do you think cardiovascular research is so important?

There has been tremendous progress in interventional cardiology. This has reduced the number of Australians dying from heart disease. However, cardiovascular disease remains the single major cause of death and disability in Australia. Further decreasing the burden from cardiovascular disease will require new knowledge about the causes underlying the disease (in addition to treatment of its symptoms). I believe that the type of research we carry out can meaningfully contribute to the gaining of such knowledge, and hence contribute to improving the health of many Australians.

What is your ultimate research goal?

It would be fantastic to identify, and then learn how to effectively modify, a key disease-causing protein or pathway. I am trying to achieve this by continuously challenging our working hypotheses and our results, as well as those published by others. I strongly believe that challenging existing dogmas and thinking outside the box is essential for, and will eventually lead to, ground-breaking discoveries.

Welcome

Welcome to the "new look" edition of the Victor Chang Cardiac Research Institute Newsletter.

It's a pleasure to share with you some of the breakthrough research taking place at the Victor Chang Cardiac Research Institute, and introduce you to some of the people whose lives have been touched by the Institute. In this issue, you'll meet Joel, a young man who is living with a serious heart condition; Professor Roland Stocker, one of our researchers investigating a disease referred to as a 'silent killer'; and Fabiola, our dedicated Bequest Relationship Manager who has a personal story about Dr Victor Chang himself.

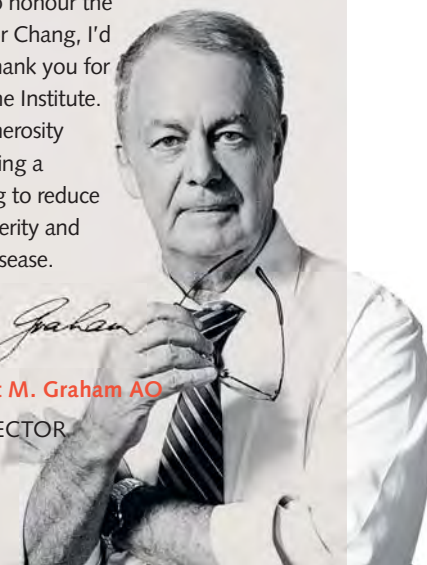
In the past year alone, our scientists, and the doctors at St. Vincent's Hospital have been involved in the first successful transplantation of a "dead" heart that had been revitalised. Our researchers have also made a discovery that could enable the repair of damaged heart tissue, which could be life-changing to the 55,000 people who suffer a heart attack each year.

You'll also find an update from our *Women Against Heart Disease Lunch*, and get the latest on the upcoming *Heart Beat Ball*, taking place at the beautiful Sydney Town Hall in September.

Heart disease remains the number one killer in this country. It doesn't matter who you are, heart disease does not discriminate. In this difficult economic climate, it's estimated that funding from government grants will decrease by a staggering 30-40 per cent over the next five years. It's vital that this setback does not deter us from reaching our goals. That's why the Institute needs your urgent and ongoing support to continue pushing research further – to improve the health and save the lives of more Australians.

As we continue to honour the legacy of Dr Victor Chang, I'd like to say a big thank you for your support of the Institute. Through your generosity you are truly making a difference, helping to reduce the incidence, severity and impact of heart disease.

Professor Robert M. Graham AO
EXECUTIVE DIRECTOR



\$6 billion

Cardiovascular disease costs Australia around \$6 billion in healthcare spending per year

4x

Four times more women die of heart disease than breast cancer in Australia

75 trillion

cells receive blood from the heart

RESEARCH UPDATE

A LIFESAVING BREAKTHROUGH

The world's first transplantation of a "dead" heart means thousands of patients could be saved each year.

In July last year, doctors at St. Vincent's Hospital successfully transplanted a heart that had stopped beating for close to 20 minutes – a breakthrough that will transform the field of organ donation. The process of revitalising a "dead" heart involves resuscitating the heart with a new console, then injecting it with a ground-breaking preservation solution that was developed by researchers at the Victor Chang Cardiac Research Institute. This preservation solution, which took 12 years to perfect, has a number of incredible benefits and effects. It reduces the amount of damage to the heart that results from a lack of oxygen by limiting the number of heart muscle cells that die. As a result, once the heart is revitalised and starts beating again, its function is improved.

According to Professor Peter Macdonald, senior staff Cardiologist at St. Vincent's Hospital and co-head of the Victor Chang Cardiac Research

Institute's Transplantation Division, six revitalised "dead" heart transplants have now been successfully performed at St. Vincent's Hospital. To date, all patients are doing well and in mid-July this year the first recipient reached her 1st anniversary.

Currently, around 100 patients are on the heart transplant list in Australia, but sadly 1 in 5 will not survive the wait. As this is largely due to the limited number of donor hearts available, it is believed that the development of this new technique will save 30 per cent more lives. Until now, Transplant Units relied solely on donor hearts from patients with no brain activity whose hearts were still beating. So the ability to transplant a heart that has stopped beating vastly increases this pool of donor hearts. For someone like 18-year-old Joel Seeto, who has recently been placed on the transplant list, this recent breakthrough could be the one that saves his life.



PHOTO: A 'heart in a box' being preserved for a heart transplantation.

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NEWS

A YEAR OF DISCOVERIES AND WORLD-FIRSTS

2015



In April this year, Professor Richard Harvey at the Victor Chang Institute in collaboration with Professor Eldad Tzahor from the Weizmann Institute, discovered a way to

stimulate muscle cell growth in the heart, limiting the damage to this vital organ after a heart attack. This exciting discovery could help the 55,000 Australians who suffer a heart attack each year.



PHOTO: Professor Richard Harvey and his research team.

2014

In another world first, our scientists develop a faster, more reliable way of diagnosing patients at risk of sudden cardiac death.

2014

Overtuning a century of dogma, we discover that the heart can regenerate in pre-adolescents, which potentially means a heart could heal itself.

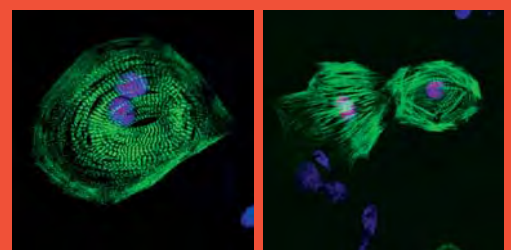


PHOTO: Heart cells at microscopic view.

1998

Victor Chang researchers participate in a major international trial that provides definitive proof that statins lower cholesterol and prevent death.

2004

For the first time Victor Chang scientists prove diseases can be **caused not only by a defective gene (mutation), but by an inherited defect in the expression of a gene (an epi-mutation).**

2014

World first transplantation of a **'dead' heart that had stopped** beating for 20 minutes, to save the lives of patients with severe heart failure.

OPEN UP YOUR HEART

A quick guide to making a Bequest in your Will

Creating your Will is a deeply personal process, and for some people it can be quite emotional. So whilst none of us wish to dwell on such topics, it is important to make each of our wishes known and respected.

We hope that you will consider leaving a gift in your Will to the Victor Chang Cardiac Research Institute. This is a powerful way to have a positive impact for future generations.

Who will benefit from leaving a gift in my Will?

How your Estate will be divided is entirely up to you. You can leave part or all of your Estate to family and friends – the Beneficiaries of your Estate – and you can also Bequest money to charities and organisations. If you choose to leave a gift to the Victor Chang Cardiac Research Institute, you will be leaving a gift to all Australians, and potentially to future generations of your own family.

Is it easy to change or add something to my Will?

If you want to change or add anything in your Will, like adding a Bequest, you don't need to start fresh. You can quickly and easily add a codicil – this is an extra instruction that becomes part of your Will. Your solicitor or trust officer will be able to tell you more.

MAKE A DONATION TODAY

Your support will help us to continue our research into cardiovascular disease, Australia's single biggest killer.

Your donation ensures Victor Chang's legacy continues by supporting the research of today's brightest heart researchers.

To make a donation or for more information call 1300 842 867 or visit www.victorchang.edu.au

MEET FABIOLA: BEQUEST RELATIONSHIP MANAGER



PHOTO: Fabiola Mougios, Bequest Relationship Manager

LOVE SHARED THROUGH THE GENERATIONS



I proudly started working at the Victor Chang Cardiac Research Institute in May this year. Being in this role feels so right. Every day I get to build authentic relationships with passionate and generous people. Everyone who leaves a bequest in their Will has a personal reason for doing so, yet they are united by one goal – a desire to help others and make a positive, long-term difference.

I had already interviewed for this job when I mentioned to my brother that I might work at the Victor Chang Cardiac Research Institute. To my surprise he said, "Dad knew Victor Chang." I was delighted at the thought that my father knew someone so amazing, but that was nothing compared to how overwhelmed I was when I heard the full story.

It was the 1980s and my dad's cousin Georgette, who was about 11 years old, had a hole in her heart. Georgette lived in Lebanon, which is where my family is originally from, so my kind, wonderful father flew her to Sydney and met with Victor Chang to arrange heart surgery for his little cousin. Dad asked Victor to post the bill to him,

but upon hearing the story Victor said that because my dad had already flown Georgette out and looked after her, he would not be charging for the surgery. After the successful operation, Georgette, who is now in her 40s, lives a healthy, happy life and is married with children.

Throughout my life I saw my father demonstrate ongoing service, humility, strength and compassion to all who crossed his path. He proudly received his OAM in 2001. Sadly, my beautiful father passed away in December 2014 but he lives on in my heart forever. I feel that dad brought me here to the Victor Chang Cardiac Research Institute to keep on sharing the love and passing it on, just as those who have left a gift in their Will are passing the love onto future generations. Everybody deserves a healthy heart, so thank you kindly to all of those wonderful individuals, past and present, who are helping to make a difference.

For a confidential discussion or information on leaving a bequest in your Will, please call Fabiola Mougios, Bequest Relationship Manager on (02) 9295 8753.



Dates for your diary...

FRIDAY 11 SEPTEMBER, 2015

The 2015 Heart Beat Ball

Location: Centennial Hall, Sydney Town Hall

Cost: \$450 per person; \$4,500 per table;
\$10,000 per corporate table

Master of Ceremonies: Sandra Sully

Enquiries: Tanya Moore at
events@victorchang.edu.au or (02) 9295 8761

FRIDAY 9 OCTOBER, 2015

Trivia Night At The Chang

Time: 7:30PM for 8PM Start

Location: Victor Chang Cardiac Research Institute,
Lowy Packer Building, 405 Liverpool Street, Darlinghurst

Cost: \$50 per person (Tables of 8 – \$400)

RSVP by Friday 2 October to Tanya Moore
events@victorchang.edu.au or (02) 9295 8761

Many prizes to be WON!

SAVE THE DATE



The 2015 Heart Beat Ball

The Victor Chang Cardiac Research Institute will celebrate its **21st Birthday** with the launch of our annual Heart Beat Ball to be held in the elegant and ornate Centennial Room at Sydney Town Hall. Come and join us as we pay tribute to the life of Dr Victor Chang and celebrate the achievements of the Institute's researchers. With the amazing **Sandra Sully as MC, a host of prominent speakers and around 500 guests**, the Heart Beat Ball is not to be missed!

PAST EVENT

Monica O'Loughlin Women Against Heart Disease Lunch

On behalf of the Victor Chang Cardiac Research Institute, we'd like to say a huge thank you to everyone who attended the *Monica O'Loughlin Women Against Heart Disease Lunch* in May this year. With 290 guests in attendance and a range of inspiring guest speakers, we're happy to announce that the event raised **\$70,000 towards vital research!** As you may know, this event was created in tribute to the much-loved wife, mother-of-three and employee of the Victor Chang Cardiac Research Institute, Monica O'Loughlin, who passed away at age 51 from an unexpected heart attack. The event was created to raise awareness of heart disease in women and raise funds for life-saving research.

We hope all of you who attended had a wonderful time, and most importantly learnt a thing or two about your heart health, the future of medical research and the vital role of female scientists.

POLO IN THE CITY

SunLux Collection by Sun International, South African Tourism and South African Airways in association with The Classic Safari Company were very proud to support the Victor Chang Cardiac Research Institute, the charitable beneficiary of Polo in the City in 2014. "We chose to partner with the Institute for Polo in the City because it is a world-class research facility that contributes in a major way to the health of all people. We, like many businesses, are committed to being actively involved in providing philanthropic support for research into heart disease which takes the life of one Australian every 12 minutes. It was particularly rewarding to be involved in Polo in the City which is aligned with our business objectives and target audience."



PHOTO: Therese Saad, Dr Nicola Smith, Ann Chang, Dr Daniela Stock

PHOTO: Prof. Kerryn Phelps AM and wife of the NSW Governor, Mrs Linda Hurley

PHOTO: Ann Chang and Amanda Keller

INVITATION – PUBLIC LECTURE

A CHANGE OF HEART – A BREATH OF FRESH AIR

Short talks on hot topics by leading heart and lung transplant doctors and researchers.

FREE ADMISSION

Date: Thursday, 29 October, 2015

Time: 2.00pm to 4.30pm

Location: NAB Auditorium (Garvan Institute of Medical Research)
384 Victoria Street (enter via Burton Street)
Darlinghurst NSW 2010

It's over 30 years since Dr Victor Chang saved 14-year-old Fiona Coote's life.

- How far have we come in Australia with heart and lung transplantation?
- How did surgeons bring a heart back to life?
- The family of an organ donor share their heart rending story.
- Heart and lung transplant recipient gives a moving account of their journey.

Health Check Booth opens at 1.00pm

RSVP (02) 9295 8600 or events@victorchang.edu.au

Sponsored by

