



**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 millions.



Sandy Di Rocco Lazarevski is grateful for every extra day she has with her two children, Alexander (7) and Simona (4).

## "YOU'RE GIVING ME HOPE", SAYS MUM OF TWO

Sandy Di Rocco Lazarevski almost died of a heart condition called spontaneous coronary artery dissection (SCAD) at the age of 28. She had no warning. SCAD is often undiagnosed, frequently fatal and affects mostly women under 55. But thanks to kind supporters like you, the Victor Chang Institute is now undertaking the first-ever Australian research program into SCAD.

Sandy Di Rocco Lazarevski was grieving the sudden death of her brother two days earlier when she was struck by blinding pain gripping her chest, nausea and dizziness.

"I thought it was just stress," she remembers.

Sadly, she was wrong. When the pain became even worse her husband called an ambulance. Within an hour of arriving at the hospital she found herself being rushed into open heart surgery. As she was wheeled into the operating theatre she wondered if she'd ever see her loving husband again.

Sandy was only 28 and apparently fit and healthy.

She had suffered an unusual and very dangerous type of heart attack, called a spontaneous coronary artery dissection (SCAD): an artery leading to her heart had spontaneously torn.

Her first thought was for her young children, Alexander, then 4, and Simona, still a baby.

"I was determined to survive," she says. "I had to – for them."

Now, the Victor Chang Cardiac Research Institute is launching the first Australian research program into SCAD.

Very little is known about the causes or triggers for SCAD, although there is emerging evidence that there may be a genetic link. Many – but not all sufferers – have recently given birth and/or have frequent migraines.

Two years later Sandy is still trying to rebuild her strength.

Every day she wakes up wondering if it will be her last.

If she gets dizzy or tired while trying to get her kids off to school, she just has to lie down until it passes, even if it makes her children late.

She can't lift things. It took months of rehabilitation to be able walk up a flight of stairs.

A possible genetic link to SCAD gives Sandy even more reason to worry for her kids.

"But I'm so grateful that we might get answers from this research, if not for me, at least for them."



**Every 12 mins**

Another Australian suffers a heart attack.



**2/3**

Families are affected by cardiovascular disease.

**40** Australians

Die because of a heart rhythm disorder everyday.

## INNOVATION & DISCOVERY



Dr James Otton

# YOU'RE INVITED: SEE LIFE SIZE 3D HEARTS THAT IMPROVE HEART SURGERY



If you're having heart surgery, you'll want to be sure your doctors are well prepared. The Victor Chang Institute's Dr James Otton puts the finishing touches on a 3D printed heart he has developed for surgeons to better plan operations and treatment.

Unique 3D models of hearts to help doctors prepare for complex surgery will be on display at the Museum of Applied Arts and Sciences (The Powerhouse Museum) from September this year. And you're invited.

**If you're having heart surgery you want to be sure that your doctors are well prepared.**

Now, thanks to work undertaken by the Victor Chang Institute cardiologist and clinical faculty member Dr James Otton, patients can have a scan of their heart.

"Then we can print out the heart in 3D so we can plan surgery and treatment," says Dr Otton.

Two of these 3D hearts – one in colour and one transparent, will be on display at 'Out of Hand', a new exhibition on display at the Powerhouse Museum from September 16.

The exhibition focuses on the use of digital design and manufacturing, such as 3D printing, in art and science.

New 3D printing technologies like this are expected to reduce the time operations take and prevent unexpected problems during surgery.

"Eventually, it's possible that fully functioning hearts could be bioprinted, with Australia at the forefront if the research is adequately funded.





## 4 Australian babies

Are born with congenital heart disease every hour.



## 30 babies

Will undergo heart surgery every week.

## 32,000

Australian children have heart disease.

### RESEARCH UPDATE

## Thank you for letting us get one step closer to finding answers to Elka's deadly heart condition

Elka was diagnosed with a 'big' heart at 7 weeks old – but not in a good way. Her heart was oversize and swollen and doctors thought she'd never make it to her 18th birthday.

At 17, Elka was in surgery having a heart transplant to fix a genetic heart problem. But she's still afraid of passing on the disorder to any children she may have in the future.

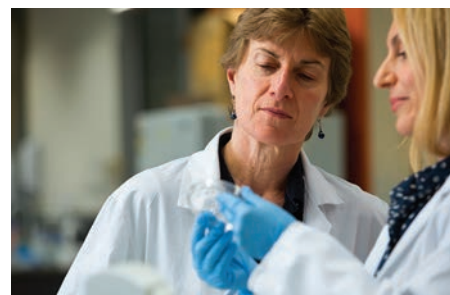
Elka was born with dilated cardiomyopathy, a heart muscle disease where the heart's main pumping chamber is enlarged and weakened. The condition is considered a major risk factor for heart failure, strokes and sudden death.

But with the help of kind supporters like you, more than 10 years of meticulous genetic research undertaken by Professor Diane Fatkin and her team at the Victor Chang Institute has identified a genetic mutation behind this deadly heart condition that affects about one in 2,000 Australians.

"Thanks to this research, people at risk can now be identified early before they have established disease, so that we can try and prevent it," Professor Fatkin said.

Genetic testing can now trace the disease in more than one in four patients well before symptoms emerge.

For Elka, it's a ray of hope. "A diagnostic test will bring some peace of mind to people like me who carry the genetic marker for this disease."



More than a decade of meticulous research by Prof Diane Fatkin (above left, with a colleague) has now identified a genetic mutation behind the deadly heart condition, dilated cardiomyopathy.



Thanks to research Elka sees a ray of hope for the future.

### NEWS

## Your researcher recognised along with Einstein, Newton and Hawking

Professor Richard Harvey, one of the first researchers to join the Victor Chang Cardiac Research Institute 20 years ago has joined Albert Einstein, Isaac Newton and Stephen Hawking as a Fellow of the Royal Society of London.

You know that your donations to heart research are making a powerful difference when one of the Victor Chang Institute's leading researchers is granted such prestigious scientific recognition.

Professor Harvey is a world-leading developmental biologist.

"It's an unbelievable honour," Professor Harvey said. "I'm really quite overwhelmed by it all."

Professor Bob Graham, Executive Director of the Victor Chang Institute said that, "the Fellowship acknowledges Richard's vital contributions to the molecular understanding of heart development and the causes of congenital heart defects".

"His work sets a level of scientific excellence that is the benchmark of the work at the Victor Chang Cardiac Research Institute."

Professor Richard Harvey



With your help ...

2014

Victor Chang researchers discover the heart can regenerate long after birth giving hope to the 2,180 babies born with heart defects every year.

2015

Your scientists discover how to limit the damage to the heart after a heart attack, which could help 55,000 Australians who suffer a heart attack each year.

2016

Professor Diane Fatkin identifies a genetic mutation behind dilated cardiomyopathy, the deadly heart condition that affects about one in 2,000 Australians.

## OPEN UP YOUR HEART

### A very beefy heartstarter

Year 12 student Jonathan Nicholls had a very important reason to work with his classmates at Murrumburrah High School to prepare a donated steer for Sydney's Royal Easter Show this year.

A year ago, Jonathan Nicholls was finding himself tired and breathless and unable to run.

He was found to need open heart surgery for a pulmonary valve replacement.

After 12 weeks recovering, Jonathan was back with his classmates preparing the steer for presentation at Sydney Royal Easter Show.

The steer was auctioned for an astounding \$22,000 to raise funds for the Victor Chang Cardiac Research Institute.

"It was a privilege to be leading the steer today. It was hard work preparing him but it was fun," Jonathan said.

Leading the steer with Jonathan was fellow Year 12 student Keegan Mainwaring who was the 2015 recipient of the Victor Chang School Science Award that recognised academic excellence in her science subjects.



Year 12 students Jonathan Nicholls and Keegan Mainwaring with the \$22,000 steer.

The Victor Chang Cardiac Research Institute relies on the generosity of kind supporters like you. But you don't have to auction a steer to raise funds!

Run a marathon, do a bike ride or hold a cake stall. To find out more call our Donor Care Coordinator on (02) 9295 8759.

Or you can choose to become a **One Heart** Partner by making a regular monthly gift.

[www.victorchang.edu.au/oneheart](http://www.victorchang.edu.au/oneheart)



## SPOTLIGHT ON

### You've helped give Joel his life back



And he and his mum want to say thank you



Eternally grateful – Joel Seeto with his mum and cousins, after his successful heart transplant.

Before his heart transplant last November, Joel Seeto, 18, couldn't even walk upstairs. Now he wants to thank supporters of the Victor Chang Institute for the research and technology that have given him his life back.

You may have received a letter a year ago about a young man called Joel Seeto, who was urgently awaiting a heart transplant.

We're sure you'll be pleased to know that Joel had a successful transplant in November 2015.

"Before my surgery, doctors used the 'heart in a box' to test if the donor's heart was right for me," says Joel.

The 'heart in a box' refers to the unique preservation solution developed at the Victor Chang Institute that helps keep a heart beating 'in a box', for up to 14 hours. It also increases the number of donor hearts available by as much as 30 percent.

#### Here's an update from Joel:

"Before the transplant I couldn't run or even go swimming with my mates. Even just resting was a struggle. It wasn't really very fun for an 18 year old."

"The first call for a heart transplant didn't work out. The heart was no good."

"Then I got another. It was pretty heavy saying goodbye to my parents. But I fully thought that I'd be okay and I didn't think it would be the end or anything. I knew I was in really good hands."

"I can't really believe that now, just a few months later, I'm thinking of joining a touch football team. It's totally different. It's crazy. Less than a year ago I would've been so out of breath and now I can run almost further than my mates and stuff like that."

I've got two thank yous. Firstly to the donor family. Thank you for the incredible gift, it's something I'll always be grateful for. And secondly to the regular donors at the Victor Chang Institute. You've made a massive difference to my life. **Thank you!**



40-50%

Of people over 65  
have high blood pressure.

3X

More women die of heart disease than  
they do of breast cancer in Australia.



Heart disease

Is Australia's single biggest killer.

## RESEARCHER PROFILE



Dr Nicola Smith, (centre) pictured here with her team at the Victor Chang Institute is determined to find a solution for the 1 in 6 Australians with high blood pressure who don't respond to available medications.

**"With you behind me, I won't stop until I have a solution."**

Name: **Doctor Nicola Smith**

Faculty: **Cardiac Receptor Biology Laboratory**

**If you're amongst the 3 million Australians who suffer from high blood pressure, then current research by pharmacologist Dr Nicola Smith could be directly relevant to you.**

Approximately 3 million Australians suffer from hypertension and if it's not managed, high blood pressure can lead to heart attack, stroke or sudden death.

There are currently six types of drugs used to control and suppress the symptoms of high blood pressure, but unfortunately the medications even in combination simply don't work for 1 in 6 sufferers.

Dr Smith's goal is to develop a new alternative drug treatment to help those sufferers who do not respond to the medications currently available.

She's deeply passionate about her work and is seen as a high achiever in her area. Having furthered her training overseas, she's been with the Victor Chang Institute since 2011.

"With fantastic supporters like you behind us, we're going to find the answers," she declares.



## Welcome

I was incredibly proud to hear that our own Professor Richard Harvey had been elected a Fellow of the Royal Society of London.

The Society is one of the most prestigious scientific bodies in the world, counting Stephen Hawking, Isaac Newton and Albert Einstein amongst its Fellows.

You may not always realise it, but supporters like you are the heartbeat of the Victor Chang Institute.

I hope that you remember this as you read about Professor Diane Fatkin's breakthrough research into the genetic cause of a type of heart disease that has been haunting families with it for decades.

And Dr Nicola Smith's work on developing a new drug treatment for the 3 million people who suffer from high blood pressure.

One of the especially exciting elements of Nicola's work is that she's not just looking for a treatment to alleviate the symptoms: she's determined to attack the cause of high blood pressure.

This research has the potential to prevent many people around the world having strokes and heart disease in the future.

I do hope you will make your way along to the Powerhouse Museum on 16 September to see Dr James Otton's 3D hearts on display. They are an extraordinary innovation for planning surgery and I believe they are just the beginning of a whole new era of technology and health.

Perhaps a time when we can print 3D organs and body parts using live tissue or stem cells is not too far away.

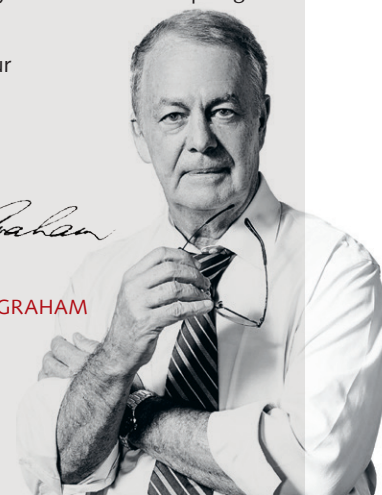
Your contributions make this cutting edge work possible. Thank you.

And don't forget the Heart Beat Ball coming up 24 September at the Sydney Town Hall. I do hope I get to see you there.

Thank you again for your generous support.

Your gifts do save lives.

**PROFESSOR ROBERT M GRAHAM**  
EXECUTIVE DIRECTOR





# Dates

for your Diaries...

**SATURDAY 24 SEPTEMBER, 2016**

**The 2016 Heart Beat Ball**

**Location:** Sydney Town Hall

**Time:** 6:30pm

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

**FRIDAY 10 MARCH, 2017**

**The Bay Soiree**

**Location:** Watsons Bay Beach

**Time:** 6:30pm

## SAVE THE DATE – 2016 HEART BEAT BALL

Paint the town red at the Victor Chang Institute's annual Heart Beat Ball to be held at the historic Sydney Town Hall on Saturday 24 September 2016.

Kick up your heels and raise funds for life-saving heart research at the same time with a glamorous Roaring Red 1920's theme.

Organise a table of friends or colleagues, and dance and dine the night away – all for a life saving cause.

You'll join an amazing crowd of generous supporters, be entertained and hear about some of the extraordinary achievements in heart research that you have made possible.

All event enquiries:  
Events Coordinator  
[events@victorchang.edu.au](mailto:events@victorchang.edu.au)  
or (02) 9295 8761.



Eurovision song contest participant Dami Im delighted the crowd at the 2015 Heart Beat Ball.



## IN MEMORY OF MONICA

### Women Against Heart Disease Lunch

If you were one of the people who attended the Women Against Heart Disease Lunch in memory of Monica O'Loughlin, thank you from the Victor Chang Cardiac Research Institute and Women In Focus CBA.

We hope you had a wonderful time and most importantly learnt a thing or two about your heart health and the importance of medical research.

A huge thanks to our Master of Ceremonies Dr Norman Swan, for bringing his expertise and passion for medical research to our cause.

Sincere thanks also to brave survivor Pamela McKenzie for sharing her extraordinary journey living with spontaneous coronary artery dissection (SCAD), and to interventional cardiologist Dr Stephanie Wilson for highlighting issues with heart disease in women.

**Left** Actor and writer Kelly Landry at the Women Against Heart Disease Lunch.

**Centre** Nicole Chettle and Dr Norman Swan show their support for Women Against Heart Disease.

**Right** The Sky News Team add their support to the fight against heart disease in women.



## PUBLIC LECTURE "STEM CELLS – HYPE AND HOPE" Sponsored by ClearView

### INVITATION

Tuesday 8 November 2016, 2pm– 5pm, followed by drinks until 6pm

#### Public Lecture

### Stem Cells – Hype and Hope

Sponsored by ClearView

**Location:** Garvan Institute of Medical Research,  
Garvan Auditorium, 384 Victoria Street Darlinghurst, NSW

**Enquiries:** [s.janis@victorchang.edu.au](mailto:s.janis@victorchang.edu.au) or (02) 9295 8763

**Cost:** FREE

