Summer Edition 2019

Victor Chang Cardiac Research Institute

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





## **40s? FEMALE? FIT?** YOU CAN STILL HAVE A HEART ATTACK

If you or someone you love is female, maybe only in her 40s or 50s and fit, she may still have a life-threatening heart disease that could strike her down at any time.

A sunny spring morning in September 2014 was almost Liza Stearn's last. She'd gone to inspect a property she and her husband were considering buying in their home town of Sydney.

While waiting a few minutes for her husband to arrive, Liza began to feel very ill, and made her way to the back garden for some fresh air.

Within minutes she felt even worse. When Liza's husband arrived he took one look at her and wanted to call an ambulance. Liza, thinking it would pass, refused.

But minutes later, she collapsed. Her pulse was erratic and an ambulance was called.

It took 30 minutes and seven shocks to restore Liza's heartbeat. It was touch and go.

A public relations professional, Liza was a fit and energetic mum of two young children. She didn't fit the stereotype of the heart attack victim.

Yet Liza was found to have spontaneous coronary artery dissection (SCAD).

SCAD is a serious condition that results when an inner layer of one of the blood vessels in

the heart tears, slowing or blocking blood flow to the heart. This then causes angina, heart attack, abnormalities in heart rhythm or sudden death.

Once thought to be rare, it's little known that 1 in 4 heart attacks in women under 50 are caused by SCAD. Its cause is unknown, but in some cases it can be associated with recent pregnancy.

The Victor Chang Cardiac Research Institute initially set out to study 40 cases of SCAD. However, some 230 cases have come to light as a result of a social media survey, and the group is growing by 1-3 new people each week.

Already 103 participants have had their whole genome sequenced, which means every gene has been mapped to look for commonalities between those with SCAD. (We'd like to do many, many more.)

Blood tests and skin biopsies will be taken to analyse what SCAD sufferers may have in common, and various stress tests run on these samples using techniques that enable the researchers to grow disease-specific cells outside the body. With the expansion of this program to a wider group of SCAD patients, the costs have dramatically increased, which is why the Victor Chang Institute is appealing to supporters for additional funding.

Liza Stearn has slowly recovered. She no longer works full time. She says her shortterm memory has been affected and she's not the woman she once was. It's had a huge impact on her life, and the lives of her family.

"For months, my son was afraid to see me leave the room. And my daughter thought I was going to die. That's taken a toll," Liza said.

"It's fantastic that the Victor Chang Institute is doing these studies. Already there's so much more known about it than there was four years ago."

SCAD is just one of the many forms of heart disease that can affect the people we love. And that's why your support for this research is so important.











## IMAGINE AN "EARLY-WARNING SYSTEM" FOR HEART ATTACKS

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If you are a supporter of the Victor Chang Institute, you have a right to feel proud of your contribution to this life-saving research. There is still a great deal of work to be done and conducting these trials takes time and funding, but your continued support means the research into the heart attack "earlywarning system" can continue. Thank you. Breakthrough research has found that it may be possible to identify those at risk of a heart attack and prevent it from happening.

The underlying cause of a heart attack is the build up of fatty material and inflammatory cells (plaque) on the inside of the heart's arteries.

It's long been the "holy grail" of cardiovascular medicine to be able to identify those particular plaques that are likely to break off, and to treat them before they cause a heart attack.

Now, as a result of the work of Professor Roland Stocker and his team at the Victor Chang Cardiac Research Institute, this may be possible.

Using a magnetic resonance imaging (MRI) scan, researchers can inject a chemical into the bloodstream to identify the presence of dangerous plaques in coronary arteries.

Once the "unstable plaque" is identified, the team administers a drug that stabilises the plaque making it less likely to rupture.

The next step in this exciting project is to carry out clinical trials on humans.

This world-first research has the potential to save countless lives by treating people who've been identified as "at risk" of a heart attack before it happens.



1 IN 10 Australians die suddenly due to an abnormal heart rhythm



affects 2 out of 3 families

58,000 Australians attended the Victor Chang Health Check Booth in 2017

RESEARCH UPDATE



Professor Sally Dunwoodie and Dr Eleni Giannoulatou are seeking to identify the genetic causes of heart defects.

## Your support is giving families answers

Why are some babies born with heart defects? You're helping to find the answers.

Every week in Australia, 42 babies are born with a heart defect, 30 have surgery and 4 will die.

In fact, heart defects are one of the most common types of birth defects.

Yet surprisingly, the cause of most heart defects remains unknown.

That's why Professor Dunwoodie and Dr Giannoulatou are working to identify the genetic causes of congenital heart disease.

Using the latest genome sequencing technology to decode the DNA of patients and their families, their approach is to look for gene mutations that have caused a baby's heart not to form properly.

114 Australian families were involved in the study.

Genetic causes were found in 3 out of every 10 cases tested, throwing new light on the causes of birth defects.

"We hope that our results exemplify how genetic testing can be used as part of patient care and, ultimately, that all babies born with a heart defect will be offered a chance of a genetic diagnosis as part of standard clinical care," Professor Dunwoodie said.





## Donations fund biggest-ever health check tour

People who live in regional and rural Australia are 50% more likely to die from cardiovascular disease.

Studies also show that hospital admissions for cardiovascular disease are far greater in regional and rural NSW than in metro areas.

That's why the Victor Chang Cardiac Research Institute is undertaking the biggest-ever Mobile Public Heart Health Check tour of NSW and the ACT.

The tour will make 50 stops and expects to check up to 6,000 people.

The tour is supported by a generous donation of \$150,000 from the IMB Bank Community Foundation, for which we are most grateful.

Living in rural or regional NSW? Get your heart health checked when our Mobile Heart Health Check visits your region.



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 leave a Bequest to the Victor Chang Institute in your Will. To find out more please visit www.victorchang.edu.au or phone (02) 9295 8759.

#### With your help ...

#### 2014

A virtual heart is developed to create a more reliable way of screening patients at risk of sudden cardiac death, which kills 25,000 Australians each year.

#### 2012

Our researchers make a landmark discovery that shows for the first time how 'nature' and 'nurture' interact to cause birth defects.

#### 2009

Researchers develop a unique preservation solution that extends the time transplant hearts can be in transit from four hours to up to 14 hours.

#### SPOTLIGHT ON

## "I wish I could have said goodbye."

No one is safe from heart disease. The Victor Chang Institute's Direct Marketing Manager, Ariana Palmisano, found that out herself when she lost her father to heart disease.

I remember the first time I heard our Executive Director Bob Graham say 'heart disease is the disease that doesn't let you say goodbye'. It felt really profound, but I never knew how true this was until it happened to me.

Since January 31 2018 – the day my father died – I have struggled every day with the pain of his loss.

Dad suffered a heart rhythm disturbance after having spent the day in the Blue Mountains with his close friend Christine. They had enjoyed a long drive together and had coffee in a café in Leura.

He had clinically died after collapsing outside Christine's house and been brought back to life. Although his heart was beating, he had severe brain damage due to a lack of oxygen for more than 20 minutes. The remaining few days of his life he spent in a coma. I sat with him in hospital, cuddling him, kissing his forehead, telling him everything I ever wanted to say to him. I told him how much I loved him, all the latest news with my twin daughters, his granddaughters Soraya and India. It was heart wrenching, and a year later it still is. It's hard to imagine that the pain will ever fade.

It was so confronting seeing my father, who was such an intelligent, strong and capable man with a wicked sense of humour and a love for life, in such a vulnerable state.

I now know first-hand why research into heart disease is so incredibly important. The people we love are everything to us and it's a human instinct to want to keep them safe.

I feel intensely grateful to every person who so kindly donates to heart research. It didn't save my Dad. But it might save someone else's.

Ariana



'Papa P' with his granddaughters, Soraya and India. "I wish so badly he was around to see my children grow up."

#### **OPEN YOUR HEART**

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Thank you for so generously sharing your stories of heart disease. It's a powerful reminder of how your gifts to heart research are a gift to us all.

## Your stories of heart disease

#### How has heart disease affected you? What makes heart research important to you?

If you are among the hundreds of supporters who shared your experience of heart disease when you responded to our recent Christmas letter, thank you.

What your responses made clear is that heart disease doesn't just affect those who experience it, but our friends and family as well.

And it has taken too many loved ones.

"I lost my beautiful son Darren at the age of 49... It is now 16 months and I still have trouble coming to terms with the loss," wrote one supporter.

"My mum died at 52 years of age (too young) from heart disease. I was 29 when that happened, now I'm 71, a *long time to live without your mum,"* wrote another.

*"My husband John (surname supplied) died next to me in bed on 19/6/1974 aged 41, leaving three young children."* 

These are just some of the stories you shared with us.

#### But there is hope.

Thanks to your wonderful support, important research into the causes and treatment of heart disease continues.

Thanks to you we now have 200 researchers dedicated to finding cures for cardiovascular disease.

And with your continued help, fewer loved ones will be taken by heart disease.



Women are 3 times more likely to die from heart disease than breast cancer 50 Australian have a heart attack each day



Professor Jamie Vandenberg, Deputy Director of the Victor Chang Cardiac Research Institute and head of the Cardiac Electrophysiology Laboratory, is trying to find out why some people develop faulty electrical circuits within the heart.

## How you are helping to prevent sudden cardiac arrest

Name: Professor Jamie Vandenberg

Faculty: Cardiac Electrophysiology Laboratory

The rhythm of every heartbeat is controlled by an electrical communications system. The regular beat of our heart is, for most of us, something we take for granted.

But for some, disturbances to this heart rhythm aren't just an unpleasant experience. They can lead to sudden and unexpected cardiac arrest and be the cause of death in approximately 1 in 8 people in Australia.

Professor Jamie Vandenberg is an internationally recognised expert in cardiac electrophysiology, which is the electrical circuitry of the heart. Thanks to the generous gifts from you and other donors, Professor Vandenberg leads a research project to find out the causes of faults in these circuits.

He and his team are investigating the molecular mechanisms underlying these abnormal electrical signals in the heart. The long-term aim is to develop better methods for assessing the risk and thereby reducing the impact of sudden cardiac death.

The team uses the most advanced equipment in Australia, enabling researchers to gain more detailed insights into why electrical signalling fails in patients with heart disease.

As Professor Vandenberg points out: "Before you can treat a patient, you need to understand the disease at a very fundamental level. Only then can you discover a cure."

## Thank you

2019 marks the 25th year of the Victor Chang Cardiac Research Institute.

In some ways it seems like yesterday that I stood on a platform with the late Diana, Princess of Wales, to open the Victor Chang Cardiac Research Institute.

is the first organ to

form in the embryo

The Institute was named after the great heart surgeon Dr Victor Chang and is dedicated to his pioneering heart research. I had the honour of looking after Victor's patients when I was a young doctor.

Central to all of our discoveries though, are our wonderful supporters.

You have helped us achieve a level of understanding and treatments that are helping Australians and people around the world.

Without you we may never have come up with the "Heart in a Box", which gives us up to 14 instead of 4 hours to transplant a heart, and we may not have learned of the importance of Vitamin B3 to a healthy pregnancy.

The highlight for me this year will be the opening of the Victor Chang Innovation Centre, which will feature some world-first equipment.

This cutting-edge technology is already giving our researchers far more detailed insights into the causes of cardiovascular disease.

Thank you, too, if you were among those who kindly shared your stories about heart disease. Your experiences remind us all of why we do what we do – and that is to save the lives and relieve the pain and suffering of those affected by heart disease.

I was particularly touched to read one reply that simply said, "I worked with Dr Chang as a nurse at St Vincent's Hospital. He was a wonderful man."

It is an honour to have you as part of the community of generous Australians sharing a dedication to finding cures for heart diseases.

PROFESSOR ROBERT M GRAHAM EXECUTIVE DIRECTOR

# CELEBRATING 25 YEARS

#### THANK YOU





Crown Princess Mary of Denmark (centre) with (L-R) a young James Packer and former wife Ericka, Sir Frank Lowy AC and Roslyn Packer, then Lady Shirley Lowy OAM and son Steven Lowy AM with his wife Judy.

Victor Chang was one of Australia's most gifted and much loved heart surgeons. He died in tragic circumstances in 1991. The Victor Chang Institute is dedicated to his memory and pioneering work.

# Thank you for 25 years of achievements in heart research

## Kind supporters like you have been there since the beginning.

Through the generosity of our supporters, the Victor Chang Cardiac Research Institute was founded in 1994.

In 1996 the Institute was officially opened by the late Diana, Princess of Wales. Beginning with just two scientists, it is now bustling with more than 300 researchers and staff.

## Thank you for choosing to support the relief of pain and suffering.

The core mission of the Victor Chang Cardiac Institute is: "The relief of pain and suffering, and the promotion of well-being, through an understanding of the fundamental mechanisms of cardiovascular biology in health and disease."

Thank you for putting yourself at the heart of that mission by supporting this research.

#### The part you continue to play.

Your continued support is vital.

Cardiovascular disease continues to wreak havoc in the community. It claims the life of one Australian every 12 minutes.

While there has been enormous progress in the treatment of cardiovascular disease (CVD), of all disease groups in Australia, it still remains the main cause of death and disability.

In fact, there are indications there is a risk of a resurgence of CVD in Australia, particularly as the population ages and because of obesity and diabetes that are now an epidemic in our community. For example, there is a higher incidence of atrial fibrillation and heart failure in the middle aged.

But with your continued support our vital research can continue.

Congratulations and thank you.

"This year, the Victor Chang Cardiac Research Institute celebrates 25 years of discoveries that we believe have contributed substantively to the prevention and treatment of heart and blood vessel diseases. These advances would not have been possible without the enormous help of generous people like you. So a very big thank you to all our supporters."

Professor Bob Graham

#### THE VICTOR CHARCE ARDIAC RESEARCH INSTITUTI



The late Diana, Princess of Wales, pictured with Executive Director Professor Bob Graham, graced the opening of the Victor Chang Cardiac Research Institute.

#### Some of the key breakthroughs you have helped us to achieve include:

**2014:** Researchers discover how to save 30% more heart transplant patients using a preservation solution and a special machine dubbed "Heart in a Box".

**2015:** We discover a way to limit damage to the heart after a heart attack potentially helping 54,000 Australians who suffer a heart attack each year.

**2017:** A landmark pregnancy breakthrough has the potential to reduce recurrent miscarriages and various birth defects globally using vitamin B3.

**2017:** Scientists at the Victor Chang Institute discover that a unique immune cell in zebrafish allows them to completely repair their injured hearts, spinal cords, and retinal tissue.

**2018:** Researchers find that a microscopic probe and an MRI scan can be used to diagnose those likely to suffer a heart attack. They also discover that high activity of an inflammatory enzyme may increase chances of a heart attack.