

Summer 2020 | Through heart surgery, Dr Victor Chang was able to save hundreds of lives. But he knew that research could save millions.



"Because of you, I get to see my son grow up"

Jayden with his son Henry. The bag Jayden is wearing carries the mechanical heart he wore for 436 days to keep him alive while waiting for a heart transplant.

At the age of 44, Jayden's mum lost her life after a dose of the flu led to heart failure.

At 46, Jayden found himself with the same heart condition in the same room of the same hospital she had died in.

The difference is that Jayden survived. What made the difference? **You did.**

It was like history repeating itself. In his mid-40s, Jayden got the flu. But it went on and on. After two months of doctor and hospital visits Jayden was so weak he couldn't stand up to throw a ball to his son.

Then it was discovered that Jayden had a swollen and weakened heart (cardiomyopathy) and was in end stage heart failure.

Jayden's flu had caused inflammation in his heart. He was only days away from death. Just like his mother.

Jayden is certain that heart research saved his life.

"The research that the Victor Chang Cardiac Research Institute is doing made it possible. I mean, I wouldn't be here. I just wouldn't be here," he says.

Jayden's biggest fear was that he wouldn't be around to see his son Henry grow up.

"Henry sat holding my hand on life-support. People told him that I was going to die."

"I said goodbye to my sister and asked her to look after my son"

Jayden spent several weeks in intensive care on life support and in a coma, then spent 436 days being kept alive with a mechanical

heart that he carried in a bag. With sheer determination he managed to climb Mount Kosciuszko from the base and participate in the City to Surf while wearing it. Then he received the ultimate gift – a heart transplant.

"Forever grateful is an understatement, it really is," says Jayden.

"I've got a chance to watch my boy grow up because of all the doctors and all the researchers."

"And I'm walking around today because people like you put your hand in your pocket. Thank you."



1 in 200 people are affected by hypertrophic cardiomyopathy



100 Australians are waiting for a heart transplant at any one point



50 Australian women have a heart attack each day

INNOVATION & DISCOVERY

You're taking heart research to new heights

Can you imagine one day having heart medications tested on your cells before it's given to you?

This is the kind of advance that researchers at the Victor Chang Cardiac Research Institute's new Innovation Centre are now working on, thanks to wonderful donors like you.

The Victor Chang Cardiac Research Institute's new Cardiovascular Stem Cell Facility combines the most advanced robotics technology with world-class equipment. This will enable scientists to study – in extraordinary detail – the molecular, cellular and tissue properties of cells from hundreds of patients, and up to 100 times faster than ever before.

This high-tech hub includes stem cell production, as well as cell function and screening. This will help scientists in their search for the fundamental reasons why some people are more susceptible to certain diseases and not others, and why some patients respond well to medication and others do not.

From congenital heart disease and arrhythmia syndromes, to atherosclerosis and ischaemic heart disease, scientists will be able to quickly identify a person's susceptibility to the most common causes of heart disease.

The new facility was funded by the NSW Government, but it is wonderful donors like you who help fund the ground breaking research being pursued there. Thank you



Professor Sally Dunwoodie, Director of the Victor Chang Cardiac Research Institute Innovation Centre



This sophisticated machine analyses heart cells and uses electrical signals to create heart beats, enabling tests to be done



This new robotic machine in the Innovation Centre generates heart cells from stem cells to improve diagnosis and treatment of heart disease

Thank you for helping to make the impossible, possible

The new Innovation Centre's cutting-edge technology and equipment will attract world class researchers to Australia, encouraging collaboration and allowing previously impossible solutions to be discovered.

And your support will help ensure that Australia's 4.2 million children and adults with cardiovascular disease receive the best possible care through research developments. Thank you.





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



Cardiovascular disease
affects 2 out of 3 families

RESEARCH UPDATE

It's devastating, sudden and silent.

But thanks to you, that's changing

As a donor to the Victor Chang Cardiac Research Institute, you have helped find a way to prevent a genetic heart disease that currently kills 1 in 200 Australians. Thank you.

With the help of kind donors like you, Professor Livia Hool and her team have made an extraordinary breakthrough in preventing a devastating heart disease



Right now, 1 in 200 Australians die from a terrible disease called hypertrophic cardiomyopathy.

It's devastating. It's sudden. And it's silent.

Hypertrophic cardiomyopathy is the leading cause of death for Australians under 40. It comes from a genetic mutation that causes the muscle of the heart to thicken and enlarge.

In fact most people don't know they have this genetic mutation until they collapse, and the outcome is fatal.

The bigger the person's heart gets the greater the chance they'll drop dead.

So the key to preventing the disease is catching it before symptoms develop.

After years of meticulous research Professor Livia Hool and her team have discovered how to do exactly that.

"First of all we worked out which channel in the heart is responsible for the energetics, and then we discovered that by targeting this calcium channel with a specific medication it can potentially prevent the disease from developing."

"When we tested it in a laboratory setting, we were able to prevent the disease from progressing altogether!"

The potential impact of this discovery is enormous.

Thanks to the support of kind donors, Professor Hool's team now has the potential to stop the disease from progressing before symptoms develop and could also reduce the risk of patients dying from sudden cardiac arrest.

Thank you for your role in achieving such a great result!

Open your heart



Wendy Vaughn-Lewis (centre)
pictured here with her parents

Wendy Vaughn-Lewis shares her gratitude

To Wendy Vaughn-Lewis, Dr Victor Chang will always be the King of Hearts for what he did for her father Norman. Wendy's appreciation will be with a bequest in her Will to the Victor Chang Cardiac Research Institute.

Should you wish to discuss including a gift in your Will, call Samantha Burns on (02) 9295 8753 and she would be delighted to speak with you.



Hello All,

My name is Wendy Vaughn-Lewis and it is both a pleasure and an honour that I write to you about Dr Victor Chang (My Hero) and my dear father Norman Lewis and the amazing surgical/life journey they went on that gave my family and I so much and showed the calibre of this great surgeon and man.

Many years ago I worked as a Cardiac Technician at St George Hospital in Sydney and during that time my father developed severely blocked arteries and was told by his cardiologists that unfortunately he was not a candidate for bypass surgery.

At that time my parents lived in Moorebank and while my father was at the local pharmacy he spoke to the pharmacist of his situation. She immediately urged him to see a Dr Victor Chang and that if anyone could help him it would be him.

My father went to see him and after Victor viewed all his medical records etc, he quietly said, "I can do your operation". My father was shocked and surprised and asked him "Why can you operate on me and no one else will touch me?" Victor said, "I can see things other people can't see".

Dad had a successful 5 vessel by-pass operation at the age of 54.

About 12 years later Dad went back to see Victor again and we found out that he would have to go through the procedure again.

He had another successful 5 vessel by-pass operation.

When Dad went back to see him in his offices some weeks after the second operation Dad looked down at Victor's notes and noticed 5 large crosses on them. He asked Victor what they meant. Victor said they showed how difficult the operation was and then added it would have been easier and quicker to give him a heart transplant. He also told Dad it was the hardest bypass operation he had ever done. I understand that because it was 5 vessels on 5 vessels and I don't think that had been done on anyone else in those times, maybe not ever. As the conversation continued he told Dad that three of his vessels were very blocked and the other 2 needed a clean up as well and said, "I thought I'd do the lot because I know I'll never have my hands on your heart again".

A short time later Victor was tragically taken from us.

What Victor left was monumental, revolutionary and an inspiring future in cardiac research and also our wonderful memories.

To me he will always be the King of Hearts.

Recently I had the great privilege of visiting the Victor Chang Cardiac Research Institute and was deeply moved and impressed by what is being forged, developed and created there. I found the scientists, researchers and staff were dedicated and impressive as they work diligently towards the full realisation of the goals of the Institute. Victor would have been so very proud.

My father lived until he was 79 years of age and he, my family and I were and are so very grateful for the years we had, the years Victor gave us. Always remembered.

Fortune can arrive in people's lives in many ways and forms. My family's greatest fortune came from Victor.

Thank you for reading this letter.

Go well,

Wendy

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 www.victorchang.edu.au or phone (02) 9295 8759.



Heart attacks claim the lives of 21 Australians every day



30 babies undergo heart surgery in Australia every week



Heart disease kills more people than any other single disease

RESEARCHER PROFILE



Dr Emily Wong

You're helping unlock the mysteries of genomics

Name: **Dr Emily Wong**

Faculty: **Regulatory Systems Laboratory**

In the early days of deciphering the human genetic makeup, Dr Emily Wong was stunned to realise that it had become possible to 'read' the genome of almost any organism on earth.

"I remember being fascinated with the diversity of animals and trying to understand how this could come about," says Dr Wong.

Now, as a researcher with the Victor Chang Cardiac Research Institute, Dr Wong uses different disciplines, especially genetics and molecular analysis, to more deeply understand what makes one cell react a certain way – or not.

"Every cell in an individual contains the same genetic information, but the exact genes that are switched on determine its identity," says Dr Wong.

Her work will help better understand how a person's traits are encoded in our genetic makeup and how systems are disrupted in disease.

"We are at an exciting time because, due to advances in technology, we can understand the cardiovascular system in a way never before possible."

"By taking a multi-disciplinary approach, we can make a big difference to understanding heart disease through discoveries in basic research, which then allows for breakthroughs in disease prevention, treatment and patient care."

The support of generous Australians like you is vital for this research. The purchase of chemicals and equipment means researchers can adopt and adapt new methods when needed.



Welcome

I am at once both proud and humbled to have recently celebrated 25 years with the Victor Chang Cardiac Research Institute.

I'm proud because of what has been achieved in that time, and humbled in the face of the great minds who wrought those achievements.

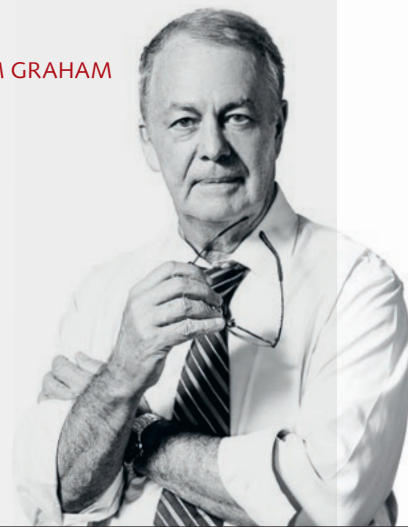
Most of all I am grateful to the wonderful people like you who have helped provide the funding that has made all this possible.

I want to let you know that for me it's time to go. I will depart the role of Executive Director in the coming months and I am looking forward to spending time with my children and grandchildren. And happily I've been assured that I'll have a desk and a laboratory at the Victor Chang Cardiac Research Institute whenever I want it.

When we started the Victor Chang Cardiac Research Institute 25 years ago there were only two of us. Now, we are almost 300.

For the period that you have been with us on this journey, you have helped make the impossible, possible. Thank you for your generosity, your kindness and your compassion. And for believing that the answers can and will be found. They will.

PROFESSOR ROBERT M GRAHAM
EXECUTIVE DIRECTOR



What's the difference between heartbreak and heart attack? Good research.



This Valentine's Day, do something
that will mean so much more to the person you love.
Donate today at victorchang.edu.au/valentine-donate



NEWS

Check yourself out – are you one of the 43%?

Last year, 1,309 people across NSW enjoyed the benefit of a free heart health check as part of the IMB 50 Stop Tour.

The Victor Chang Cardiac Research Institute Heart Health Checks toured 22 locations covering the Hunter Region, Central Coast, Sydney and Greater Western Sydney.

Participants have their heart health tested by looking at blood pressure, blood sugar and cholesterol levels.

It pays to check your heart health – 43% of those tested had risky results and were referred to their GP.

The tour was kindly supported by a generous donation of \$150,000 from the IMB Bank Community Foundation.



One of our nurses conducting a heart health test in Sydney's south west

Who was tested?

**1,309
PEOPLE
WERE
TESTED**

60% were female and **40%** were male
76% were greater than 40 years of age
24% were less than 40 years of age
43% of those tested were referred to their GP

SPOTLIGHT ON

Celebrating our budding young scientists

Last year, 248 bright, young Year 11 students from over 160 schools were commended for excelling in science and presented with a Victor Chang Cardiac Research Institute School Science Award at local ceremonies across NSW.

The award has been developed to foster and encourage an interest in science among secondary school students. The awards are based on a firm belief that for Australia to be at the forefront of innovation and medical



Some deserving recipients of the Victor Chang Cardiac Research Institute's School Science Awards 2019

advancements, our young people need to be encouraged to pursue science.

To honour the students and encourage further study, a number of our leading scientists attend ceremonies to congratulate the winning students and share their insights into why they should consider studying science.

"The best part about having a career in science is that it allows you to contribute newly discovered knowledge to the world, which can directly better society," says Executive Director, Professor Robert Graham. Congratulations to all of our incredible 2019 School Science Award winners!