



Victor Chang
Cardiac Research Institute

THE BEAT

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



LITTLE KIDS GET HEART DISEASE TOO



Baby Charlie after a gruelling 10-hour heart operation. Your support for research into congenital heart disease helps protect children and their families against suffering

The worst moment in the lives of Charlie's parents was seeing their three-month-old baby go into cardiac arrest in front of their eyes.

Kate had an uneventful pregnancy and birth with Charlie. The only difference, compared to her other two children, was that Charlie was smaller than his brother and sister.

He ate little and didn't grow much. So after three months he was admitted to Canberra Hospital to be, as his mum put it, "fattened up".

As it turned out, Kate says, "If we'd waited another week, Charlie wouldn't have survived".

Charlie's heart had swollen to four times its normal size. He was suffering from end-stage heart failure.

Charlie was rushed to The Children's Hospital at Westmead in Sydney by helicopter. He was found to have various congenital heart

diseases including hypoplastic aortic arch and multiple large holes between the two lower chambers in the heart, called ventricular septal defects (VSDs).

For 10 hours the surgeons operated. And for 10 hours his heartbroken parents waited anxiously for news.

As their baby was wheeled out of surgery, all the alarms went off. Charlie was having a cardiac arrest.

"The scariest thing was watching them do CPR on our tiny baby. Then they wheeled in the heart-lung machine. Then suddenly, his tiny heart started beating again," says Kate.

In Australia, 1 in 100 babies are born with congenital heart disease (CHD). In most cases, a genetic diagnosis is not made.

That's why – with your help – scientists at the Victor Chang Cardiac Research Institute are trying to understand the full genomics of CHD to work out its causes and the risk of recurrence.

In cases where a mutated gene causes more than just heart defects, knowing exactly what the gene mutation is helps clinicians manage those other conditions. This is especially important in those cases where some of the effects of the mutation can only be seen later in life.

Charlie is now two and a half. His parents try to treat him just as they treat their other children, but they – understandably – can't help but be a little protective.



The more we know about congenital heart disease, the more we can do about it. That's why your support is so important. The work you help fund at the Victor Chang Cardiac Research Institute aims to deepen our knowledge of congenital heart disease, because it is only then that treatments, cures and ways of preventing it can be found.

1
250

Cardiomyopathy affects
up to 1 in 250 Australians



1 in 4
people who get sepsis
don't survive



1 in 100
babies are born
with heart disease

INNOVATION & DISCOVERY

YOU HELP BRING NEW HOPE TO SUFFERERS OF SEPTICAEMIA

Sepsis is a serious blood infection caused by bacteria. It's commonly known as blood poisoning and has an extraordinarily high fatality rate of more than 25 percent. It claims the lives of 100 Australians each week.

But scientists at the Victor Chang Cardiac Research Institute, led by Professor Roland Stocker, have found a new cause of very low blood pressure, which is one hallmark of sepsis.

The low blood pressure in septicemic patients means the "amount of blood the heart can transport to the peripheral organs is decreased," says Professor Stocker.

The peripheral organs then don't get

enough oxygen and nutrients, and "this can result in multiple organ failure and that's what people die from," he said.

The research found that a previously unknown molecule, called cis-WOOH, dramatically dilates blood vessels, which causes this profoundly low blood pressure.

Professor Stocker said the discovery paves the way for scientists to explore a potential treatment to reduce the death rate of

people who contract sepsis.

"Sepsis is a complicated disorder, so our finding is potentially extremely significant. It could also possibly be used to develop treatments for other inflammatory conditions such as certain types of heart disease, neurological disorders like multiple sclerosis, and perhaps even the inflammatory components of cancer," Professor Stocker said.



Korina, pictured here with her husband and two children, lost both legs and both forearms, and the tip of her nose to sepsis, and only narrowly escaped death. "We had never heard of sepsis before I got sick. But since then we've been doing everything in our power to get the word out," she says.



100 Australians die every week from sepsis. Korina narrowly avoided being one of them

In April 2015 Korina was loving life.

"I was happy, healthy, had an incredible husband and two young children aged three and just five months. I came down with what we thought was the flu, I then developed gastro symptoms and visited a GP," she says.

"The next day I was deteriorating and went to the local hospital. From there it was a fight for my life."

"A couple of days later I was in severe septic shock. I had full organ failure and my heart stopped."

"My extremities were starved of blood and oxygen and subsequently died."

"I required a quadruple amputation (both arms below elbow, left above knee, right below knee)."

"I also required extensive grafts to the majority of my body and lost the tip of my nose, requiring a skin flap from my forehead."



Every 26 minutes
heart disease claims
the life of one Australian



Cardiovascular disease
affects 2 out of 3 families



100 Australians
are waiting for an urgent
heart transplant

RESEARCH UPDATE



Unlocking the secret of how hearts can repair themselves

Why does your heart stop repairing itself as you grow up?

Dr Siiri Iismaa is trying to work out why and how heart muscle cells can regenerate to some extent when we are babies, but stop regenerating as we grow up.

Heart disease can result from an insufficient number of functional heart muscle cells.

There are many reasons someone may not have enough heart muscle cells: a heart attack, an intrinsic heart muscle cell disorder, or disrupted heart growth in childhood due to congenital heart disease, prematurity or malnutrition.

What you probably didn't know is that for a period after birth, mammals, including humans, can actively regenerate their heart once heart muscle cells are able to divide.

This is how the heart grows during childhood. But this regenerative capacity of the heart is lost by adolescence as heart muscle cells mature and stop being able to split.

As a result, the heart is unable to repair areas that are damaged.

But Dr Siiri Iismaa – one of the Victor Chang Cardiac Research Institute's senior staff scientists - aims to decipher the molecular basis of postnatal heart muscle cell maturation, and why and how cells stop dividing.

Understanding this process will mean scientists may be able to identify targets or biochemical pathways that can potentially be altered. With your help, scientists may be able to work out how to encourage the heart to repair and regenerate itself, not just in children but also in adults.

If the research is successful, you'll have helped bring it to fruition to benefit heart patients in Australia and around the world.

NEWS



Genetic analysis tells us more about the causes of heart disease

Imagine one day going to your doctor to be checked out for heart disease and having your entire genome sequenced to detect the cause of your illness.

It could happen.

Through recent research, Professor Diane Fatkin of the Victor Chang Cardiac Research Institute has discovered clear benefits to sequencing someone's entire genome to help find the causes of cardiomyopathy.

Professor Fatkin has found that genome sequencing is a sensitive, and more comprehensive test than is currently used clinically, and that it provides rich additional information likely to be valuable in the future.

Cardiomyopathy is an inherited disease that causes the heart to weaken and enlarge. It affects up to 1 in 250 Australians and it is the single most common reason for heart transplantation.

With the help of generous supporters, Professor Fatkin and her team were able to map the entire genomes of 42 patients. They found the genetic causes of more cases of dilated cardiomyopathy than the standard test, which only looks at a restricted set of heart disease genes. The team also found many genetic variants that may be unrecognised causes of cardiomyopathy which can now be further researched.



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 ...

2017

A double pregnancy breakthrough, with the potential to reduce recurrent miscarriages and various birth defects globally by using vitamin B3.

2017

Zebrafish are found to be key to completely repairing their own damaged hearts, eyes, retinas and spinal cords. Our scientists are using zebrafish to explore the potential of self-healing in humans.

2018

Our scientists have developed an 'early warning system' to help identify and treat people at high risk of heart attack – and prevent it from occurring.

SPOTLIGHT ON

“I have been very lucky”

For Christmas 2016 Jonathan Poole (known as 'Jono') and his family wanted just one thing – a new heart for Jono.

At 21 Jono had already had two major heart surgeries and his heart was operating at just 17% of capacity.

A heart transplant was his only hope.

For nine months he waited. Then the phone rang to let him know there was a heart available for him.

Now, two years later, Jono is fit and well.

“I have been very lucky,” says Jono.

“While there was a tiny bout of rejection which required me to take transplant medication, my body has adapted really well. The first thing I noticed was my hands and feet. I always used to have cold hands and feet, but I woke up and they were warm. I spent 8 days in hospital, but I was up and about in 1-2 days.”

“The highlight has been being able to do stuff that previously I couldn't. My friends are quite active and before my heart transplant I couldn't participate in whatever they were doing – like bushwalks and harbour runs.”

“Now I can participate. Feels great! I swim most days. I am back at work, back at university, just living and enjoying life.”



Jono pictured here, finally got a new heart two years ago and is thoroughly enjoying his newfound energy.



When we first wrote about Jono in 2016, many supporters kindly sent their best wishes to Jono and his family. Here are some of them.

OPEN YOUR HEART



Krythia lost her father and her uncle to heart disease and has decided to include a gift to the Victor Chang Cardiac Research Institute in her Will.

Why Krythia has decided to leave a gift in her Will

Krythia is deeply saddened by the knowledge that so many tiny babies need heart surgery at such a young age.

For her, “only through research can we move forward and find causes and cures for the heart diseases cruelly killing so many each day”.

That's why Krythia has chosen to include a gift to heart research in her Will.

If you, like Krythia, find inspiration in the idea of future generations one day living without heart disease, you'll find it very easy to include a gift in your Will too.

Your Will is a very personal matter, and we would encourage everyone to provide for family first.

One hundred percent of any gift in your Will goes to research into cardiovascular diseases, funding – in your honour - innovative ideas that could lead to world first treatments, speed up lifesaving discoveries or train the next generation of researchers.



“I want to help”

“Heart disease runs in my family, sadly killing my father, grandfather and uncle. I want to help, which is why I decided to leave a bequest to the Victor Chang Cardiac Research Institute.

I was incredibly inspired after visiting the Institute and talking to the staff about their work.

Genetic research is an area I am very interested in and it saddens me to hear of young babies having to have major heart surgery when they have been in the world for just a few hours.

Thankfully the Institute is helping families know in advance the likelihood of their children being born with congenital heart disease.

I also heard of another amazing discovery in heart transplantation where doctors can now keep a heart beating outside of the body for an additional 14 hours, thanks to the groundbreaking research at the Institute.”



100 Australians
a week die of septicaemia



30 babies
undergo heart surgery
in Australia every week



Cardiomyopathy is the
single most common reason
for heart transplantation

RESEARCHER PROFILE



Dr Anita Ayer

You're helping make some heart diseases a thing of the past

Name: **Dr Anita Ayer**

Faculty: **Vascular Biology Laboratory**

Dr Anita Ayer was inspired to become a scientist by her mum, who was also a scientist.

"I remember going to work with my mum and being given little 'jobs' around the lab and loving every minute," Dr Ayer says.

As she grew up, Dr Ayer realised that contributing to science and medical research was how she wanted to change the world. Working at the Victor Chang Cardiac Research Institute allows her to realise that dream.

Dr Ayer works in the Vascular Biology laboratory and focuses on understanding how coenzyme Q levels can be increased in people with heart disease. (Coenzyme Q is an antioxidant produced naturally by the body. It is often found to be low in people with heart disease.)

"We believe that the development of new methods to increase coenzyme Q in cells represents an innovative and novel strategy to restore heart function and prevent failing hearts. Currently, no treatment approaches the management of cardiovascular diseases via this strategy, making research of this kind highly unique and valuable," says Dr Ayer.

But she and the rest of her team can't do it alone.

"It costs about \$2,000 just to carry out one experiment and that's just for the chemicals and materials we use to grow the cells!" says Dr Ayer.

"Given that my project works across disciplines using yeast cells and mammalian cell lines, the work is carried out simultaneously, the costs add up easily!"

For Dr Ayer, your support for heart research is vital.

"I doubt there is anyone that hasn't been affected by heart disease in his or her family or community," she says.

"Research into heart disease is vital so that the diseases that are so common today become a thing of the past."



Welcome

We couldn't do it without you

More people die of heart diseases than any other single cause.

But somehow it still seems worse when we see it in young children, especially babies like little Charlie.

I guess it's a natural human trait to feel protective towards our most vulnerable members.

That's one of the reasons why research into congenital heart defects and postnatal heart development are so important. If children are to grow up into adults, they need to survive childhood.

On another front, Professor Stocker's amazing breakthrough in septicaemia opens a new front for research into treating this disorder that right now is killing 100 Australians a week.

Commonly known as blood poisoning, one in four people with septicaemia don't survive.

And it is truly heart-warming to hear of people like Krythia, who has so kindly included a gift to the Victor Chang Cardiac Research Institute in her Will.

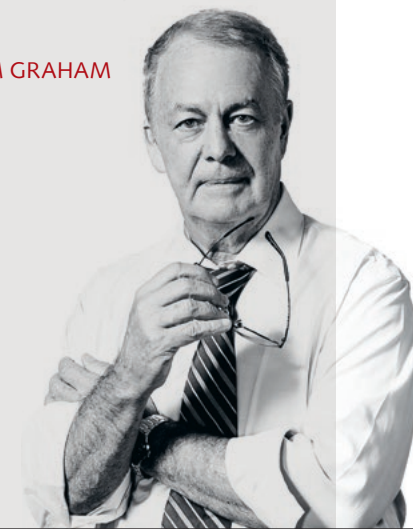
Including a gift in your Will is simple and anyone can do it. You don't have to be wealthy – gifts of any size are enormously appreciated.

When you leave a gift, you are making sure that heart research will continue to save people's lives, even when you are no longer here to see it.

Thank you for whatever support you give. We couldn't do what we do without you.

Robert M. Graham

PROFESSOR ROBERT M GRAHAM
EXECUTIVE DIRECTOR



Above and beyond THE HEART OF GOLD AWARDS



THANK YOU

PREPARE TO BE INSPIRED! Every year the Victor Chang Cardiac Research Institute's Heart of Gold awards honour members of the Australian community who have gone above and beyond to try and save the life of someone suffering from a heart attack or cardiac arrest.

Colin almost didn't get to see his new baby

On Australia Day 2017, Colin Winn and his heavily pregnant partner, Karen Clark, were in their Coogee apartment when Colin, 46, started to feel "quite funny".

Colin took some paracetamol and went for a nap. When he woke up, he was in St Vincent's Hospital having suffered a cardiac arrest.

When Colin lay down Karen was concerned. Colin had just come back from the gym and he looked very flustered. Ten minutes later, Karen

noticed he looked "really stiff" and "looked like he was having a seizure".

Quickly Karen put Colin into the recovery position and called 000. At eight and a half months pregnant, it was no easy task to drag her partner onto the floor, where she performed CPR for 10 minutes until paramedics arrived.

Karen saved Colin's life. Three weeks later, Karen gave birth to a little girl they named Juliet. Colin was by her side.



Thanks to quick action by heavily pregnant Karen, Colin survived to see baby Juliet born.

Bystanders rally to save a life

On a rainy morning, 69-year-old business owner Andrew Goldfinch, was walking his two dogs on Bondi Beach as he usually did.

Driving home, unknown to him, he blacked out and crashed into parked cars.

Lisa Delle Donne was waiting at the bus stop on her way to work when she saw a car accelerate wildly through an intersection and crash.

Lisa ran over to find the driver unconscious, struggling to breathe, with his foot stuck on the accelerator. She quickly called 000.

Tony Steiner, a local plumber heard the impact and saw an unresponsive man at the wheel. By chance, Tony's good friend Warren Rosen was driving past so Tony flagged him down to help.

Together, they lifted the man out of the vehicle and placed him on the ground.

Nurse Amy Mathew was driving her two sons to soccer practice when she saw the commotion. She ran across the road and saw that the driver's skin looked grey, he was making "gurgle" sounds and felt stone cold so she immediately began CPR. Pumping the man's chest over and over, Amy, Warren and Tony continued compressions for 10 minutes until paramedics arrived on scene.

Andrew has no recollection of the accident. But he knows that if it had happened 5 minutes later when he arrived home, no one would have found him for days, because his wife was overseas at the time.



Paramedics take over from courageous bystanders resuscitating Andrew Goldfinch after he had a cardiac arrest while driving.

A story of courage

Just before Christmas, 17-year-old Jesse and his 13-year-old brother Ben sat down to have dinner with their parents, Robyn and Lloyd Baldwin. Lloyd was laughing and joking with his sons. Suddenly, midsentence, Lloyd gave a loud cough followed by a jerk then his head hit the table.

With his history of sleep issues, the family thought he had just nodded off. The boys started to ask 'Dad, are you okay?' but there was no response.

Jesse touched him and realised his father's skin felt very cold. Jessie immediately rang 000 and with the help of Ben moved Lloyd to the floor.

At the time, their mum Robyn says she was completely "frozen" and stood by while the two boys took charge, trying to save their dad's life.

Following instructions from the Control Centre Officer at 000, Jessie started CPR on his dad. The boys remained composed and continued compressions until paramedics arrived, but their father, just 46 at the time, sadly did not survive.

Jesse and Ben were nominated for their Heart of Gold award by their mum for their outstanding courage under the most difficult of circumstances.



Jesse and Ben, with their mum Robyn, did everything they possibly could to save the life of their father Lloyd.