Spring Edition 2018



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



~

Sally's Dad holding his eldest grandchild. Sadly, he would never get to meet his youngest.

DAD, I MISS YOU

"There's a gaping hole in my life where my Dad used to be," said Sally Crocker of her much loved father, who died three years ago from heart failure

Sally's Dad lived alone. He was only 66.

At the age of 50 he'd had a quadruple bypass and he was due for another. Heart disease ran in his family. He'd lost both of his parents to heart attacks.

Sally was broken by her Dad's death. He was her rock, always there for her, always there for her children.

It's a story that tens of thousands of Australians can relate to.

That's why work being undertaken by the Victor Chang Institute's Dr Kazu Kikuchi is so important.

Dr Kikuchi is working with zebrafish (see below) to understand just how certain cells can repair damaged hearts, spinal cords and retinas in these tiny freshwater fish.

The hope is that one day, the research will tell us how human hearts can repair themselves too.

With three young children of her own, Sally hopes that by the time her children reach her father's age, cures like this are available to them.

It's research being done now that has huge potential for children of the future.

This fish could hold the secret to repairing your own heart

Dr Kazu Kikuchi of the Victor Chang Institute and his team have made a remarkable discovery: a unique immune cell is critical for allowing complete repair of not only damaged hearts and spinal cords, but also injured retinal tissue.

Imagine if humans could do that – regenerate your own heart, spinal cord and the retina in your eyes.

What the scientists have found is a special group of cells in zebrafish known as regulatory T cells (Tregs). These immune cells have the capacity to cluster around an injured area and produce special chemicals that allow the damaged area to completely regenerate.

The research is at very early stages but it's very exciting. It's a world-first discovery and it provides major new insights into the possibility of regenerating organs and tissues that in humans currently cannot be repaired after injury.

"If we can manipulate human T-reg cells to cure heart disease, repair vision loss and reverse spinal cord damage, the implications are likely to be huge", said Dr Kikuchi.



Zebrafish have the ability to repair damage to their own hearts, retinas and spinal cords.





A baby is born with congenital heart disease every **4 hours**







YOU'RE HELPING THE WORLD FIND OUT HOW HEARTS ARE REALLY FORMED



Again you've helped support another world first discovery. Thank you. A whole new dimension of knowledge about how hearts are formed, is opening up huge possibilities for treating and preventing heart disease in the future.

With the support of wonderful donors like you, senior scientist Dr Del Monte Nieto, working alongside Professor Richard Harvey, has discovered exactly how the heart chambers grow from a simple microscopic tube with specialised domains into complex pumping chambers.

A unique feature of these chambers is the spongy, inner layer that forms in a segmented way (like Lego blocks clicked together). If this does not form correctly it can potentially result in premature death of the developing baby or serious congenital heart defects.

The research has also shown the chambers of the heart begin to develop much earlier than previously thought. This suggests that heart defects may also develop at a much earlier stage in the womb as well.

"This new knowledge is vital for understanding heart defects in babies and, in the future, for how we might approach the design of new treatments," said Professor Harvey.

There is still a long way to go, but this paradigm shifting discovery, made with the help of kind supporters, is a first step towards new and effective treatments for congenital heart disease in the future.

 $40^{\%}$ of people with cardiovascular disease do not have modifiable risk factors



leart disease remains the **Single** biggest killer of all Australians

RESEARCH UPDATE

Will you help improve transplant survival rates?

It can be difficult to get a heart transplant. Then when you've finally received one and undergone major surgery, you still have a high possibility of some kind of rejection.

Most people who have a life-saving heart transplant will experience some form of organ rejection in the first year of their transplant. About 90% survive their first year and after 25 years survival rates fall to just 15%.

At the moment, determining whether the patient's body is rejecting the heart requires an invasive biopsy. One in eight biopsy results show significant organ rejection and doctors need to calculate the level and the suitability of immunosuppressive treatments needed.

Associate Professor Andrew Jabbour and his team hope to reduce or eliminate the need for invasive biopsies and ultimately improve survival rates by using Magnetic Resonance Imaging (MRI) to monitor the rejection rate in heart transplant patients. This method is faster and more accurate which improves outcomes for patients.

One clinical trial has been undertaken already but further trials are needed. It is hoped the findings from heart transplants will also apply to other transplants such as kidney, lung and liver.



Dr Andrew Jabbour is determined to find a less invasive, faster and more effective way to identify organ rejection after heart transplantation.



Without successful heart transplants, people like 18 year old Joel simply wouldn't survive.

NEWS



Professor Diane Fatkin and her team are working on the genetic causes of dilated cardiomyopathy and atrial fibrillation.

Finding the genetic links to dilated cardiomyopathy

Analysing genomes from 200 families using the 'Gene Machine'

Identifying the genetic causes of dilated cardiomyopathy and atrial fibrillation is closer than ever with the use of the "Gene Machine", a sophisticated piece of gene analysis technology that can map a person's entire genome in two days. (The first time a person's entire genome was sequenced it took 12 years!)

As a result of being one of only a small number with access to this technology, Professor Diane Fatkin from the Victor Chang Institute has confirmed that a particular genetic mutation in a heart protein called titin is involved in dilated cardiomyopathy and atrial fibrillation.

The next stage in the project is to sequence the DNA of more than 200 families to identify any new disease genes for dilated cardiomyopathy and atrial fibrillation.

Family members who have the genetic mutation and are at risk of developing the disease are identified. Treatment can begin which may delay or stop the progression of the disease to heart failure.

Your continued support for this ground-breaking research is bringing hope to many families. Early treatment can prevent their loved ones from developing heart failure in the future. Thank you.

With your help ...

2017

Scientists at the Victor Chang Institute have discovered that a unique immune cell in zebrafish is critical for allowing complete repair of not only damaged hearts and spinal cords but also injured retinal tissue.

2017

A landmark pregnancy breakthrough by scientists at the Victor Chang Institute has the potential to reduce recurrent miscarriages and various birth defects globally using vitamin B3.

2017

In a world-first discovery our scientists unlock the mystery of how heart chambers are formed in utero, opening up huge possibilities for treating and preventing heart disease in the future.

OPEN YOUR HEART

Five year old Leo, "has more heart than anyone I know", says his proud dad.

Would you guess that Leo was born with only half a heart?

Jacinta and her husband Justin were very excited when they went for their 20-week ultrasound. That is until they received the devastating news that their baby boy had hypoplastic left heart syndrome.

He would be born with only half a heart.

Leo's first major open-heart surgery occurred three days after his birth. At the ripe old age of five Leo has already undergone two more surgeries.

Now, instead of struggling to walk due to shortness of breath, Leo is running and throwing the ball around and has even joined an Auskick team.

Professor Richard Harvey's study of hypoplastic left heart syndrome is using stem cells to search for a genetic pattern that leads to childhood heart disease.

If you'd like to help Leo and other children like him call 1300 842 867 or go to www.victorchang.edu.au to make your donation.



Making the impossible, possible



Kate Phillips is competing in Ironman competitions five years after a heart lung transplant.

Kate always loved sport but sport didn't love her.

Born with a hole in her heart, Kate had surgery at 10 months old.

She loved soccer and running, but her breathlessness meant she couldn't run more than 200 metres without passing out and couldn't take part in sports like cross country.

It wasn't until her heart and lung transplant in 2013, at the age of 27, that a whole new world was unlocked for her.

Two months after the transplant Kate walked the 5km Bridge to Brisbane. Eighteen months later she did the bike leg in a team with her brother at the Noosa Triathlon and the following year, she did her first sprint triathlon at Raby Bay.

Now five years after the intense emotion of a miraculous and traumatic operation, Kate pursued yet another one of her dreams – participating in a full Ironman event in Cairns.

Congratulations Kate! Kate will be the guest speaker at our upcoming Women Against Heart Disease Lunch in Sydney.

If you're inspired to run for fitness and fun, why not join a community fun run like the City to Surf? You can even fundraise online for the Victor Chang Institute simply and easily by going to everydayhero.com.au to set up your own fundraising page and stay in touch with your sponsors.



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 our website at www.victorchang.edu.au or phone our Donor Care Coordinator on (02) 9295 8759.



40 Australians die of a heart rhythm disorder every day



affects two out of three families



Every 26 minutes heart disease claims the life of one Australian



Dr Alastair Stewart, head of the Victor Chang Institute's Structural Biology Laboratory, is enquiring into the tiny microscopic generators inside every cell of our bodies.

Unlocking the secrets to the energy of life

Name: Doctor Alastair Stewart

Faculty: Structural Biology Laboratory

Inside every cell of our body we have thousands of microscopic generators and Dr Alastair Stewart is fascinated by them. These generators spin thousands of times a minute, generating all the energy we need to perform at every step, thought and heartbeat of our lives.

The existence of these microscopic generators has been known for many decades, but science is still far from understanding how they actually work.

Why is this important?

Only by seeing the machinery of life at the atomic scale can we begin to understand life and disease.

These generators are miniscule, just a millionth of a centimetre across, so conventional technology is not powerful enough.

To throw more light on exactly how these tiny generators work and their role in disease, Dr Stewart's team uses a myriad of extremely complex technologies and experimental methods (such as X-ray crystallography, electron microscopy and intact mass spectrometry).

"I love the discovery process," says Dr Stewart. "It's innate within us: it's the same reason we took to the oceans to discover the world and why we sent 12 people to step on the moon."

"Seeing the machinery of life is a great privilege that I'm very lucky to have and getting to tell these stories to the rest of the world is a fantastic feeling."

Thank you

Even after all my years in heart research and cardiology I am still deeply moved to see a child, like five year old Leo, going strong after being born with only half a heart.

It really is a miracle of modern medicine.

Thank you to everyone who has contributed in any way to the success of the Victor Chang Institute.

I'm very excited about Dr Kikuchi's discovery that zebrafish can regrow spinal cord, retinas, and hearts. Imagine if in decades to come humans could do the same thing.

Dr Del Monte Nieto's work alongside Professor Richard Harvey on exactly how the heart chambers grow from a simple microscopic tube with specialised domains into pumping chambers, has added remarkable new knowledge to how babies' hearts are formed.

Professor Diane Fatkin and her team are making strides in their research to find the genetic links to dilated cardiomyopathy.

I could go on. But my point here is that there are many extraordinary pieces of research being undertaken at the Victor Chang Institute and you are an important part of that. While government grants provide some of the costs for this research, they only provide part of the total costs. Thus, philanthropic funding is still desperately needed to allow us to delve into whole new areas that are not yet sufficiently developed to receive a government grant.

Thank you for all that you do.

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PROFESSOR ROBERT M GRAHAM EXECUTIVE DIRECTOR



THURSDAY 16 AUGUST, 2018 Women Against Heart Disease Lunch

Datesfor yourDiaries...Location: Shangri La SydneyTime: 12noon – 3:00pmCost: \$180 per person including GSTMC: Edwina Bartholomew,
Sunrise Presenter
Dress: A touch of red

SATURDAY 15 SEPTEMBER, 2018 Heart of the West Ball

Location: Marconi Club, Bossley Park Time: 7:00pm Cost: \$175 or \$1,750 per table of 10 Dress: Black Tie Hollywood

FRIDAY 16 NOVEMBER, 2018 Sohn Hearts & Minds Investment Leaders Conference

Location: Hamer Hall, Arts Centre Melbourne Time: 8:30am – 3:00pm Tickets: \$3,000 per person Details: www.sohnheartsandminds.com.au

SAVE THE DATE

2018 Women Against Heart Disease Lunch

Join us on Thursday 16 August and book your tickets for the 2018 Women Against Heart Disease Lunch at the Shangri La Sydney.

Be inspired by the incredible Kate Phillips, who, only two years after a heart and lung transplant began competing in various sporting events culminating in an Ironman event.

The Women Against Heart Disease lunch was established seven years ago after the Victor Chang Institute's Finance Manager, Monica O'Loughlin, tragically died of a heart attack, leaving behind a loving husband and five beautiful children. Since then the Victor Chang Institute has been committed to raising awareness about the risk for women with heart disease.

Heart disease is the most common cause of death in women, claiming three times as many lives as breast cancer.

Vitally, women need to know that they can have different heart attack symptoms to men. Many are unaware that instead of chest pains, women often have nausea, indigestion and shoulder ache.

Tickets are selling fast so don't miss out. Event enquiries: events@victorchang.edu.au or (02) 9295 8761



Jaynie Seal, Sky News Anchor, Women Against Heart Disease Lunch 2017.

2018 BAY SOIRÉE

A few spots of rain didn't dampen spirits at the Victor Chang Institute's Cuban inspired 2018 Bay Soirée held in February.

Guests made the most of the lovely rosé and champagne, Heineken and delicious Mojitos.

As always, entertainer Todd McKenney did a sensational job hosting the evening. Few could forget his moving interview with Saasha and Simon Scaife, the parents of three year old Charlotte. When Charlotte was born the middle part of her heart, including the valves, hadn't formed normally. She also had numerous holes and her heart was double the normal size for her age. Thank you, Saasha and Simon, for giving us a rare insight into your raw experience with heart disease.

This annual event would not be possible without the generous support of Fraser Short and the team at the Watsons Bay Boutique Hotel. To everyone who attended, volunteers, committee members, sponsors and donors – thank you.

The funds raised will help support a young scientist in their work to find cures for congenital heart disease, one of the most common forms of birth defect in Australia and the world.

> Cuban inspired 2018 Bay Soirée on the beach at Watson's Bay; Centre; Gavin Rakoczy, Jonathan Henry, Marcus Chang and Joel Barbuto; Right: Alexi Baker and Zofi Paterson.

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



HEART of the WEST

SAVE THE DATE

7pm Saturday, 15 September 2018 Marconi Club, 121 Prairie Vale Road, Bossley Park Tickets: \$175 or \$1,750 per table of 10 Dress Code: Black Tie Hollywood



