It was an average but beautiful and sunny Sydney winter day when Lisa Genovese’s life suddenly changed.

After an early dentist appointment, Lisa headed to work. She had felt nauseous on and off for a few days but didn’t think much of it and got on with her busy schedule.

After parking her car, Lisa suddenly felt sicker than she ever had before and lay down on the ground. A few moments later she felt a little better so she decided to hurry on to work. Lisa got up and started walking down the street but a few moments later she collapsed. Lisa suffered a sudden cardiac arrest. Thankfully a kind passer-by saw her fall and unable to move, so called an ambulance to take her to Royal North Shore Hospital.

Lisa was shocked that her heart was making her so ill. “When it happened I thought – what’s wrong with me? Do I have cancer?” While Lisa was unconscious, the Paramedics performed CPR on her to keep her alive. The Paramedics were doing such a good job that during CPR she came to again and told the Paramedics that she was ok, in time with the CPR compressions. “I thought I was fine, but my heart was in a weird rhythm and even though I had become conscious again, it was necessary for the Paramedic to use a defibrillator on me.”

After thorough investigation, it was discovered that Lisa had a narrowing of the right coronary artery in two spots — a tiny but dangerous clot had formed. The clot dissolved within several days and mysteriously Lisa’s tests showed she again seemed to have a perfectly normal and healthy heart.

“If this experience has taught me anything, it’s to make the most of each day and our lives. I want to know more about why this happened to me and I know that can only happen with research. My symptoms were nothing like those you see on TV or in movies of people having a heart attack.”

“Even though I didn’t feel well, I dismissed it and got on with my busy life – like so many women do each day. I want women to understand they don’t always get the typical warning signs, and to be aware and act if something doesn’t seem right.”

“Growing up in the 70’s, Lisa heard about Dr Victor Chang and thought he was an amazing man but she didn’t think much about it or that his work and legacy would some day affect her directly.

“Only one in three women experience ‘typical’ heart attack symptoms such as chest pain.

“Our bodies are amazing and complex and when something goes wrong, it’s not easy to know why. Thankfully dedicated scientists like the team at the Victor Chang Cardiac Research Institute are making discoveries and breakthroughs every year that influence how people with heart disease are treated now and in the future.”

Research saves lives and one thing that this experience has taught Lisa is that you don’t know how close you might come to heart disease affecting you or someone you love one day. Lisa is excited about the research taking place at the Institute. “We don’t have to be the researcher in the lab to make a difference. Research can save hundreds of thousands of people and by supporting research I feel like I’m part of the team.”
$1 spent on medical research produces more than $2 in health benefits to the economy.

The biggest weight increases have occurred in people of reproductive age, and that means that there is an increasing number of babies being born to parents that are overweight or obese. Traditionally, the health of the baby’s mother has been the primary focus when considering the health of the child growing in the womb, as well as after birth. A/Prof Suter has challenged the notion that a mother’s health is solely responsible for her child’s health by examining the role of the father before the baby is conceived.

A/Prof Suter heads the Epigenetics laboratory at the Victor Chang Cardiac Research Institute where she performs research into the way genes are expressed and what this means for common human disease. A/Prof Suter and her team have been looking at the effects of parental obesity on the health of the father’s child as well as the health of future generations of children.

They have found that babies born to healthy mothers, but with obese fathers, are predisposed to having a metabolic syndrome later in life – fatty liver disease for example, particularly if they are exposed to a Western style diet. Thus, despite the sole focus to date on the mother’s health and its impact on a baby, A/Prof Suter has shown that the father’s health is important too.

Most remarkably, the team have also shown that the predisposition to disease due to dad’s obesity, not only affects his child but also future generations – in other words, the grandchildren of the overweight or obese father are also predisposed to metabolic disease. The next step in the research is to understand how this can happen. By doing so, ways to modify lifestyle to correct the epigenetic defects could be discovered, which would improve the health not only of the father’s children but also his grandchildren and great grandchildren.

Why is Epigenetics research so important?

Epigenetics is the way that our genes are regulated but we still don’t really understand how it works. This research is innovative – about the big picture. Epigenetics will lead to real biologically meaningful insight on human disease, for today and future generations.

Welcome

Happy New Year! It is with gratitude that we celebrate the start of 2016 here at the Victor Chang Cardiac Research Institute. We look back on a successful year of research in 2015. Research that would not have been possible without the generosity of our supporters – so thank you!

In this issue of The Beat, you’ll meet Lisa, a seemingly healthy woman, shocked by a sudden cardiac arrest, and Associate Professor Cath Suter, one of our researchers, who is investigating the link between a father’s health before a baby is conceived and the impact on his baby’s future health.

You’ll also find an update from our Heart Beat Ball held at beautiful Sydney Town Hall and our Public Lecture, hosted by Jessica Rowe.

In 2016, be sure to mark the dates in your diary for the Woman Against Heart Disease Lunch and our Bay Soiree, which will be held on the sand at the picturesque Watson’s Bay Boutique Hotel.

Times are challenging and we have a tough year ahead. In 2015, The National Health and Medical Research Council only funded 13% of the projects submitted. This is the lowest success rate in the 75-year history of the NHMRC. This is having a flow on effect – forcing scientists at the top of their games to leave and join overseas organisations in order to make the next step in their career, instead of staying in the Australian science and medical community.

Because of the limited government funds available, we are now more reliant than ever on our community’s support if we are to continue to try and rid the world of heart disease.

We are so grateful for your ongoing support to this vital and lifesaving research. Rest assure, your contributions, large and small are making a difference!
A new technique has been discovered to grow heart cells outside the body that is faster, cheaper and more efficient.

Before this landmark breakthrough, growing heart cells had been a cumbersome and time consuming task with poor results. Heart cells are vital to medical research and the treatment of heart disease.

Dr Alexis Bosman and PhD student, Hananeh Fonoudi, were determined to overcome this problem. Dr Bosman explains: “We grow and study heart cells to find out what causes different types of heart problems. I’ve worked to make heart cells for a long time and it’s always been such a struggle to do it efficiently”.

It took two years of extensive research but Dr Bosman and her team have made a breakthrough that has tripled the number of heart cells scientists can grow outside the body. “By tinkering with the traditional recipe, we’ve discovered how to produce billions of heart cells in a quarter of the time”, said Dr Bosman.

The new technique is faster and far more cost effective, saving as much as $20,000 a year.

This discovery will have huge implications in several areas:

- Scientists will be able to study the heart cells to understand how heart defects develop.
- Pharmaceutical companies could soon be able to use these cells to test the effects of their drugs on the heart, on a larger scale and at a more economical rate.

A very exciting prospect is the possibility to use these cells in regenerative medicine – for example, replacing damaged heart cells that have been irreparably injured after a heart attack.

With one Australian every eleven minutes suffering a heart attack, this breakthrough could have a real impact on the future of heart disease in Australia and the world.
Arhythmia is one of the most common causes of death in Australia – a life-threatening, electrical disorder which stops the heart pumping blood effectively, causing sudden death.

Since his world-first breakthrough in 2014, Dr Adam Hill has been trying to develop a better test to help diagnose patients with Long QT Syndrome. In the past, this deadly disease has been notoriously difficult to diagnose.

Using high performance computing techniques, Dr Hill, together with colleague Professor Jamie Vandenberg, have worked out a better way to diagnose patients suffering from Long QT syndrome. Using a computer process, they analyse a patient’s electrocardiogram (ECG). The team has already tested and diagnosed more than 200 patients with 90% accuracy. Dr Hill explained: “This research is hugely exciting! We were able to identify why some patients have abnormal ECG signals, and how a person’s genetic background can affect the severity of their disease. In the past, we were limited because we didn’t have the computational grunt to do an effective job.”

The use of the CSIRO’s multi-million dollar Bragg ‘super-computer’ made the analysis possible – in comparison to a regular PC, the same analysis would take 21 years to achieve.

It’s been a busy 12 months for Dr Hill, who has also been handpicked to help overhaul aspects of the world’s pharmaceutical guidelines. The project has been labelled the “most important revisions in cardiovascular safety in more than a decade”. In this role, Dr Hill is helping revolutionise cardiovascular risk assessment, enabling new medications to reach more patients in need.

Scientists at the Victor Chang Cardiac Research Institute, in collaboration with the Lieber Institute in the USA have discovered a better, more personalised way of treating patients with schizophrenia.

Patients with schizophrenia are three times more likely to die of sudden cardiac death because their medication suppresses a channel in the heart which is vital to regulating the heart’s rhythm.

Professor Jamie Vandenberg, has analysed six common antipsychotic drugs to see how they affected the heart and the brain of patients with schizophrenia. “We discovered a domino effect between the medication, the patient’s metabolism and their genetic predisposition to schizophrenia” Professor Vandenberg explained.

This ground-breaking study could allow people suffering from schizophrenia to lead a more normal life – identifying the best drug for each patient.

The Victor Chang Cardiac Research Institute is at the forefront of a huge paradigm shift in genetic research. Working in collaboration with our colleagues at the Garvan Institute of Medical Research, our scientists now have access to a $10 million ‘Gene Machine’ which is revolutionising the way they conduct research.

This incredibly advanced technology will enable the Victor Chang Institute to screen 100% of the human genome – analysing every single gene and every single strand of DNA. The impact of this will be enormous.

It’s believed genetic research will uncover the causes of these horrible diseases. This promises far more answers for the parents of a sick baby and for struggling patients longing to find out why their hearts are failing. Doctors will also be able to tell families the likelihood of having another baby with a heart problem. But most importantly, scientists will develop better treatments, bringing us a step closer to the ultimate goal – prevention.

The first time scientists sequenced the entire genetic makeup of a human it took them 12 years and cost $3.2 billion. Using this advanced technology, it costs as little as $1,800 and the new ‘Gene Machine’ can sequence 350 human genomes per week!
Why I Give – Najat Harmis

Regular giving – One Heart Partners launch with testimonial of longstanding regular giver.

Najat decided to support the Victor Chang Cardiac Research Institute in 1998 after having a look at her family and realising how prevalent heart disease was.

Six people in her family have undergone life-saving surgery – some only in their 30’s! Najat also lost a cousin in his mid-40’s from a major heart attack.

“It was the thought of possibly losing so many people who are dear to me that prompted me to donate. I feel like I’m investing in my future family and the future of many generations to come.”

“I find supporting through regular giving really convenient as the donation is deducted from my bank account automatically each month. Even though my $60 a month might not seem like a lot, it all adds up and I know my small part is making a difference.”

“I didn’t know Dr Victor Chang personally but I was always inspired by the work he did. I support the Institute because I want to feel like I’m doing my bit to carry on his legacy and make a difference for my future family.”

Name: Suzy Hur
Age: 23
Title: Scientist

Research field:
Suzy’s research focuses on inherited obesity and diabetes. A baby’s health has long been considered a mother’s responsibility as soon as she falls pregnant. Sashimi, soft cheeses and raw eggs are all off mum’s menu when she is eating for two! But what about what Dad’s been eating? Suzy’s research indicates that what a father eats before a child is conceived could also have an impact on the future baby’s health.

What are you most passionate about?
I am passionate about education! I believe education is a basic human right and through awareness and education we can resolve many global challenges such as disease, poverty and climate change.

What do you love about being a scientist?
As a scientist you spend your time trying to discover something new or exploring questions that no one has been able to answer. This requires you to be highly imaginative! I think science also challenges you to stay open minded in spite of your depth of knowledge and to remain unbiased.

Name: Celine Santiago
Age: 23
Title: Biologist

Research field:
Celine is trying to discover better ways to prevent and diagnose heart diseases. She spends most of her time working in a zebrafish aquarium at the Victor Chang Institute studying these remarkable creatures that can regenerate their hearts after injury, just like a lizard can grow its tail back.

What is your favourite area of your research and why?
I love working with zebrafish every day to understand how they regenerate their hearts. These fish may have the answer to ways humans can also renew their hearts after they’ve been damaged by a heart attack. Currently, many millions of heart cells are lost after a heart attack.

What do you love about being a scientist?
I actually love the idea that I’m just a tiny piece of a global puzzle. It’s very exciting!
The 2016 Bay Soiree
“A night to remember”

The inaugural Victor Chang Heart Beat Ball was a brilliant success! The vital funds raised by the Ball will help our dedicated scientists continue working towards a cure for congenital heart disease, the most common form of birth defect in Australia and the world.

The Town Hall looked majestic – from the ‘human’ red carpet to the welcoming trumpet players, and the luxurious Champagne Bar, courtesy of sponsor, Laurent Perrier – we hope it was a night to remember.

Our sincere thanks go to everyone who attended, our elegant host Sandra Sully and our moving speaker, young mother Kirsteen Martin, whose little baby Lara has already been through so much.

The night would not have been possible without our incredible committee members, volunteers and our sponsors: Virgin Australia, Fairmont Hotels and Resorts, Emirates, Crown Resorts, Laurent Perrier, Paul Gauguin Cruises, Wiltrans, Rocky Mountaineer and LK Boutique who kindly donated the His & Her Cartier timepieces for the Treasure Chest.

What a wonderful way to celebrate our 21st birthday and to honour the legacy of Dr Victor Chang!

Hundreds attended the Victor Chang Institute Public Lecture ‘A Change of Heart, A Breath of Fresh Air’ held in conjunction with our 16th International Symposium to hear some of the world’s best doctors share their insights into heart transplantation.

Hosted by Channel Ten’s Jessica Rowe, the program featured short talks about this remarkable procedure. Associate Professor Kumud Dhital chaired the event, alongside guest speakers from Donate Life, The Organ and Tissue Authority, and surgeons from St Vincent’s Hospital.

The audience also heard from two incredible Australians whose lives have been changed forever by organ donation. We are grateful to guest speaker Philippa Delahoy for bravely sharing her story. Philippa tragically lost her husband Scott when he was just 44 years old. The couple had discussed organ donation before, which helped Philippa honour his wishes. The day Philippa donated Scott’s organs was the proudest day of her life. “It was the day Scott became a hero and saved lives,” Philippa shared.

Special thanks to all of our guest speakers for an enlightening and informative afternoon.