

1 June 2021



Dear Valued Supporter

Imagine being 24, with your whole life ahead of you and you find out that you have a problem with not only your heart valve but also your aorta!

To top that off, you were born with a hole in your heart.

Well, meet Jivani.

Jivani came to see me in 2019 at the young age (for heart surgery) of 24. She already had a long history of needing corrective heart surgery for a condition that she was born with through no fault of her own, **Bicuspid Aortic Valve**. This is a condition we often see because we are a team that specialises in aortic surgery and in particular congenital valve surgery.

Many of our patients have either a problem with the valve or a problem with the aorta, but unfortunately for Jivani, she had a problem with the valve and the aorta and in addition, was born with a hole in the heart. These conditions all combine to form what we call a left heart complex.

This condition has resulted in several corrective operations over the years for Jivani and I was introduced to her before the very last one.

Jivani is fortunate. Her recent aortic surgery should see her out for the rest of her life. We have replaced the aortic valve which has given her a functional valve and the ascending aorta (the aorta in the chest above the heart), all of which have removed the risk to Jivani of sudden rupture and therefore death.

Jivani is obviously ecstatic that she has the rest of her life ahead of her, but we urgently need your help to ensure that others are saved from a similar predicament.

Because of donors just like you, The Baird Institute can research conditions like Jivani's and how things such as genetics and blood flow play a part. This work is long and arduous, often taking many years until root causes are found.

Saving lives takes time and it also takes you! We can't save lives without you.

Heart research is very expensive, in fact no other medical research costs more. It is imperative to find a cure for Bicuspid Aortic Valve Disease, the most common congenital cardiac defect that affects 1-2% of the population. Had we not operated on Jivani using the knowledge we had garnered from our research, she most likely would have died. As she tells us, she has now been given another chance at life.

Donors like you have given Jivani that third chance.

What you may not know, is that we do not receive any government funding to do our work. We depend on people just like you who see the importance of giving people another chance at life.

We are the only dedicated cardiothoracic surgical training and research institute in Australia. There is no one else doing the kind of research that we do.

Plain and simple, your donation will help us to save even more lives and find the root causes of genetic mutations so we can predict people's likelihood of having an aneurysm, individualise their treatment and better advise patients, like Jivani, on subjects such as starting a family and the possible risks for their children.



Jivani is celebrating with her family because you gave her a third chance at life.

Every gift is appreciated and will be put directly to our work whether its \$50, \$250, or even \$500. The more you give, the quicker we can do our research and the more lives that can be saved.

Just complete the donation form overleaf and send it to us in the mail or go to our website and donate online.

While we have such amazing stories to tell, the untold stories of tomorrow are what make The Baird Institute matter the most. Please give today and let us count on you to provide others like Jivani the opportunity to experience a third chance.

With deep gratitude for everything you make possible. You are an important member of our team.

**Professor Paul Bannon PhD MB BS FRACS
Chair, The Baird Institute**

A Third Chance At Life

My name is Jivani and I am twenty-five years old. I am incredibly honoured and humbled to write my story for The Baird Institute. It is a story about which I often keep quiet, but now I hope it can be shared as an inspiration to many.

It is because of your commitment to and investment in research and technology that I am here today and can share my story with you.

I was born in 1996 to my amazing parents and a family who adored me. I had my whole life ahead of me. At 8 days old, I went for a regular check-up with my mum where they would discover that I had a severe hole in my heart that needed attention. This was my first encounter with open-heart surgery at 10 days of age.

When I was 7 years of age and in year one, I was enjoying primary school and like any child, just wanted to be with my friends and have fun. Life was a little different for me though, and I never quite knew why.

Mum and Dad often pulled me out of school early sometimes to take me to cardiologist appointments - I thought all kids did this. I had ultrasounds and could hear my heart beating but I could also hear Mum crying at the end of the bed and I was clueless as to what was going on.

Little did I know that at seven years of age, I would have my second open-heart surgery to repair the hole in my heart that was slowly affecting my whole body.

I felt normal; life with a hole in your heart feels normal when that's all you know.

But check out the photo below, I could barely crack a smile with my best friend! Looking back now, it is difficult to see myself so young, and so ill.



There are so many Jivanis waiting to be helped. Can they count on you?



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7 Days Till Christmas

Towards the end of 2019, I was a full-time university student studying criminology and was involved in activities like gymnastics, fitness classes and working part time at a furniture store. For me, life revolved around making it to a workout class and submitting university assignments on time. I was always very active, despite the previous surgeries, so I barely knew what it felt like to feel ill or tired anymore. I had just finished a fitness class at 8AM and felt like I was on top of the world – unfortunately, this was not the case. I noticed that I couldn't catch my breath and it was taking me a while to form sentences, without running out of air in my lungs. I tried so hard to convince myself that it wasn't my heart (because this was always at the back of my mind).

After a day or two I took myself to my local GP, who thought it could have been stress. What followed was an array of tests, hospital visits, cardiologist and heart surgeon appointments and many ultrasounds that proved that yes, I was experiencing heart failure and the leakage from my heart was putting significant strain on my lungs; they were slowly filling up with fluid. Each day it was getting more difficult for me to breathe and simple things, like taking a shower, felt like I was running a marathon.

I was experiencing severe heart failure, and at 23, I felt like my life was over.

A third open heart surgery was planned with Professor Bannon as my surgeon. Before I could even begin to comprehend it I was lying in a hospital bed awaiting surgery. There were 7 days till Christmas, and all I kept thinking was whether I would be out in time for family Christmas celebrations?

Another Chance

When I woke up in the ICU after surgery, I felt like I had been hit by a semi-trailer. Every time I moved; I thought my chest would tear apart. I had a million tubes connected to me and all I felt was the excruciating pain in my chest. I could barely keep my eyes open for 2 minutes before I drifted off. My lungs felt heavy, my chest was on fire and my throat was dry for the first few days after surgery. Within a blink of the eye however, I was five days post-surgery and feeling ok. This was a miracle for me. I was discharged from hospital on Christmas Day, 2019 and got to spend the day at home with my family.

When I look back at this moment, it doesn't feel real. I get emotional about it, and I often think I can't put it any other way than to say I have had a third chance at life. Despite having had two prior surgeries, my third surgery truly saved my life.

Having the surgery was a pinnacle moment for me, it changed everything. I became more in tune with my body and my physical health; I became more focused on staying happy and surrounding myself with positive people.

I am now able to attend the gym regularly and spend time with my wonderful family and I have the support of my partner when life gets tough. Now I have the opportunity to inspire people through my third chance at life.

It has become a tradition for my family and I to donate to The Baird Institute each year as our way of thanking them for all their hard work AND for saving my life. I owe it to Professor Bannon, his team at The Baird Institute and to you for every tick that my mechanical valve makes, for every breath that I get to share with my loved ones and for every bit of life I get to enjoy today. This is the profound and life changing impact that scientific research and technology can have on saving the lives of those who need open-heart surgery.

Please donate now to The Baird Institute in their appeal to save lives. They saved mine and may one day save yours!



YOUR GENEROUS GIFT IS VITAL FOR THE CONTINUATION OF OUR RESEARCH

The Baird Institute receives no government funding. To do our work we rely heavily on the generosity of our supporters, many of whom are current or former patients of the cardiothoracic surgeons from Royal Prince Alfred Hospital who are associated with The Baird Institute. Our goal is to give people a second chance to live a full and healthy life. Few gifts are more precious than that!

Please support us today. Your support will save lives.

WAYS TO GIVE QUICKLY AND EASILY

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On occasion we will send you email updates about our work, while your date of birth helps us to distinguish donors with the same name

MY GIFT

☐ Yes, I would like to make a gift to support The Baird Institute Research and Training Program

☐ **Single donation Amount** and/or ☐ **Regular Monthly Donation Amount ***
○ \$50 ○ \$100 ○ \$200 ○ \$ _____ \$ _____ (minimum \$25 a month)

* A **regular** tax-deductible donation of \$25 or more **per month** entitles you to become a **Partner in Research**. Your regular gift will ensure that we have the necessary funds available to help ordinary people as they battle unexpected, life threatening diseases of the heart and lungs. As a **Partner in Research**, you will receive The Baird Institute newsletters and invitations to special events. For more information, contact Catherine on 02 9550 2350

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A GIFT IN YOUR WILL:

If you would like to be sent information on leaving a gift in your will, please tick here ☐

If you would like to advise us that you have already left a gift in your will, please tick here ☐

Please contact Catherine on 02 9550 2350 for further information or a confidential discussion

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