THE BAIRD INSTITUTE
Applied heart & lung surgical research

PO Box M85, Missenden Rd, NSW, 2050
www.bairdinstitute.org.au

WE NEED your help

1 June 2020

Dear Valued Supporter

For you, the 9th of October 2018 may have been a run-of-the-mill forgettable day - get up, coffee, work, light exercise, dinner, family time. The usual. But for me, it was the day, at age 31, that I underwent open-heart surgery.

Flashback to 1989 and I had just turned 2 years old. I kept running into glass doors and Mum questioned my eyesight, or lack thereof. She waltzed into the ophthalmologist's office, aiming for a glasses prescription before we'd head to David Jones for lunch. Instead, she was being handed documents and scripts to take me to the Children's Hospital. Dr Martin had calmly highlighted he suspected I had **Marfan Syndrome** - a connective tissue mutation where the most fatal aspect of Marfans involves the heart.

I remember well the run-down lime-green walls of the old Children's Hospital in Camperdown. Dr Martin had been on the money all from a simple eye exam. The tests came back confirming I had **Marfan Syndrome.** We never made it to David Jones that day.

The Red Zone

With Marfans, the aorta is about twice the size of an average person's. The biggest risk is that if it doesn't stop growing, it 'dissects' (splits in half) with a high chance of fatality. To reduce the chances of that happening, open-heart surgery is required to spare the valve.

Every year since I was 2, I had been monitored annually. Hooked up to echocardiograms and the growth of the aorta measured until I'd reach that at risk 'red zone'. I'd somehow made it to 30 without needing the jaws of life, but stats showed it was just around the bend.

I figured if I could train my physical and mental bodies it would help me to prepare for the worst-case scenario should it hit. My regimen involved a personal trainer, Saturday pump classes, long distance ocean swimming, mindset coaching, a nutritional program and advice from an estate planner on how to structure my finances if I did pass away. About 18 months into this regime my cardiologist found a minor growth and decided we'd need the surgery in a matter of weeks.

Before I knew it…

It was the night before my operation. After having the last full meal I'd eat in 10 days I started my first round of sedation medication. Little did I know it was the last time I'd be able to lie down flat on my back for 3 months without feeling like a knife was going through my torso and swing my legs over the bed without a rope. Or laugh, or give a hug without feeling like my chest would burst in half.

I woke up the next day, had my antibacterial shower and said my final goodbyes to my family and was hooked up to oxygen.

I was carted into the preoperative theatre and the nurses kindly told me I'd experience a bit of tingling in my left arm...That's the last conscious moment I remember with my old heart.

Everest

Something must have gone well, because I woke up in ICU. Everything about my physical body was immobile leaving nothing but my eyes and lips that could move freely without support or excruciating pain.

By the next day, I hadn't slept for about 48 hours, eaten anything for 3 days and the anaesthetic and horse-tranquiliser pain medication had made its last run.

I felt like I had been hit by 10 semi-trailers and like Mt Everest was growing from my neck to my navel, it was pain like nothing I'd ever known. The medication in itself was sickening, and I could hardly keep it down. The weight of the excess fluid was taking its toll, I was now 10kgs heavier and I hadn't moved in days. I could feel my lungs heaving, every breath felt like I was lifting bricks in my back and my body had gotten so heavy not having moved. I was covered in tubes and drains from across and down my neck, across, underneath and in my ribcage and drips down both arms. I wanted to cry from the pain, vomit from the medication and collapse from exhaustion, I had nothing left in my tank. I felt depleted. Empty. Beaten up. This was the test that all the training had prepared me for.

The next 3 hours were the longest, toughest and most excruciating minutes of my life that felt like days. My Mum and Sister were at the end of my bed, experiencing a world of pain of their own, watching me fade. They put on a brave face, making light jokes and making sure I knew that they loved me. I couldn't speak or return their messages of love. Mum said she just heard my screams looking into my eyes.

And then some sort of miracle happened. The nurse said I was getting better quickly, and they could move me out of ICU into my own room…much much quicker than they had expected. I had no idea what had happened, all I knew was that I was out of the risk-zone, and I could finally sleep without worrying I might not wake up again. I slept for pretty much 4 days straight after that. It wasn't exactly easy afterwards, but I knew the worst was over.

I am incredibly honoured, and humbled to write my story for The Baird Institute. It is because of the Institute's research and investment in technology that I'm alive today. You could say (prepare for a bad pun) that's it's close to my heart! It's also the reason that in a few years' time, anyone going through this experience may not need their chest broken, but a small incision will suffice. This is the profound impact scientific research and technology can have on the lives of us that can't escape open-heart surgery, so please support The Baird Institute's 2020 Mid-Year Appeal.

This is an excerpt from Rebecca's LinkedIn blog post which you can read at:
https://www.linkedin.com/pulse/intimate-heart-rebecca-mason/

"The next 3 hours were the longest, toughest and most excruciating minutes of my life that felt like days. My Mum and Sister were at the end of my bed, experiencing a world of pain of their own, watching me fade."

Dear Friends,

I hope you are all keeping well during these unprecedented times.

It is tremendously heart-warming for me to hear Rebecca's story and how well she has done post-surgery. She truly is an inspiration! Rebecca was diagnosed with **Marfan Sydnrome** at a very young age and is one of the many patients that we at The Baird Institute have been able to help. Rebecca was referred to me by her cardiologist in 2018 and an operation followed soon after.

On the back of the well-established Aortic Diseases Clinic at Royal Prince Alfred Hospital (RPAH), co-founded by Professor Richmond Jeremy and I, we have established multiple arms of research looking at the varying stages of aortic disease. These include basic scientific research in the laboratory to determine the factors (both inherited and social) that lead to the development of aortic aneurysm disease in addition to interventions to stop that process. Some other areas of research are of course related to the best ways to treat already developed Aortic Aneurysm Disease surgically, with the best quality of life and survival outcomes. Suffice to say, the areas of research are a wide-ranging umbrella that cover all aspects, and this is typical of the multi-disciplinary approach that we take clinically as well as scientifically at The Baird Institute.

When this Aortic Diseases Clinic began it was known as the Marfans clinic because **Marfan Syndrome** is the best known of the inherited aortic diseases. It is the treatment of these **Marfan** patients that we use as a benchmark when we measure ourselves and our success rates in treating this disease. Treating someone with **Marfan Syndrome** is often about treating a family and treating them for life and as such, gives us a real chance to get to know them which is always a great joy and a great privilege.

As health care professionals, we are trying every day to make lives better for those many Australians diagnosed with some form of disease affecting the heart, lung, chest wall and diaphragm that is treatable with surgery. These people are now more vulnerable than ever due to the Coronavirus.

As always, we thank you most sincerely for your past support. Without it, our work would not continue. Because of the Coronavirus, our organisation, like many other charities, has been negatively impacted with a large reduction in our income stream. Your continued support will provide the next phase of resilience for The Baird Institute, one that will provide a lifeline for so many. If you can support this Mid-Year Appeal 2020, please know that your trust and assistance is valued by every member of our team. Your generous gift of $50, $200 or $500 will go directly towards maintaining our research and training initiatives – initiatives which have a direct impact on people like Rebecca and the on health of more than 1/3 of Australia's population, so please support us today.

With sincere thanks.

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

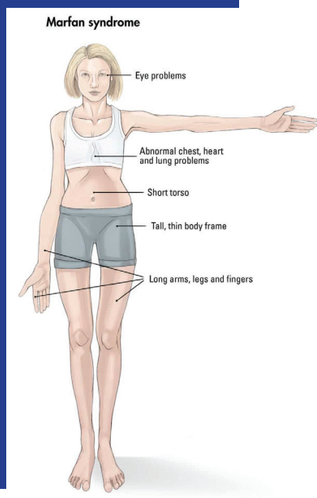
Marfan Syndrome is a genetic disorder of the body's connective tissue, which may affect the heart, eyes, skeleton and lungs. Connective tissue holds all the body's cells, organs and tissue together and offers support to many structures, including bones, tendons, ligaments, cartilage, heart valves and blood vessels. It also plays an important role in helping the body to grow and develop properly.

It is caused by a defect in the gene that enables your body to produce a protein that helps give connective tissue its elasticity and strength. About 1 in 5000 people have **Marfan Syndrome**. While approximately 75% of cases are inherited, some, such as Rebecca's, are due to a spontaneous change in a gene (a mutation which happened during the baby's development in the womb), with no family history at all.

Signs and symptoms of **Marfan syndrome** are different for everyone. Sometimes they appear when a child is very young, as they did for Rebecca, or they may not show up until later in life as a teenager or an adult. Individuals with Marfans are usually very tall and thin, have elongated fingers and toes and have an arm span that exceeds their body height. Other common features include a long and narrow face, crowded teeth, an abnormal curvature of the spine.

The most dangerous complications of **Marfan syndrome** involve the heart and blood vessels. Faulty connective tissue can weaken the aorta — the major artery of the body – which can in turn cause it to tear or expand under pressure (for example during exercise) thus resulting in an aortic dissection or aneurysm. Heart valve malformations are also common for those with **Marfan Sydnrome** because they have weaker tissue than normal in their heart valves. If your doctor suspects **Marfan syndrome**, one of the first tests they may recommend is an echocardiogram which captures real-time images of your heart in motion. If you are diagnosed with **Marfan syndrome**, you will need to have regular imaging tests to monitor the size and condition of your aorta.

There is currently no cure for **Marfan Sydnrome**, but it can be managed with careful monitoring, medication, surgery and lifestyle changes. As a result, early and accurate diagnosis is essential.



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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 surgeons 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.

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☐ 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 $20 a month)

***** A **regular** tax-deductible donation of $20 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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