



## Jordan Bailey – Age 9

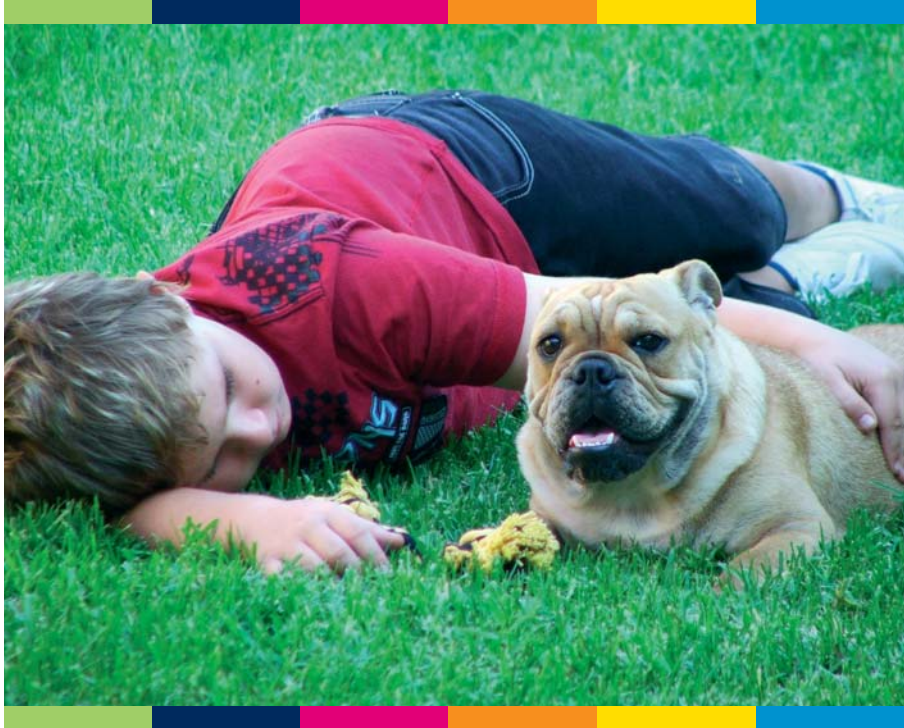
- A friendly, outgoing boy who is very sympathetic and aware of other people's needs.
- Loves rugby league, V8 supercars, the Wallabies and his mini Australian bulldog, Bella.
- Dislikes sausages and capsicum.
- Wants to be a veterinarian when he grows up.
- Diagnosed with a very rare heart defect when he was just six years old.



The Children's Hospital at Westmead often organises visits from celebrities and sporting stars to help lift the spirits of the sick kids in the wards. When Jordan's favourite player, Rhys Wesser from Penrith Panthers, visited him in Hospital after his surgery, young Jordan was absolutely thrilled and just couldn't stop smiling! Since then, Jordan has enjoyed meeting many of the players and even had the chance to be 'water boy' for the team. He has now started playing football himself and simply loves it!

# a patient's journey

## Jordan's story



Jordan's best friend, Bella.

Jordan was an IVF baby and, to his parents' joy, seemed a perfectly normal, healthy child. Then, at ten months, he started displaying signs of breathlessness and a barking cough. The paediatrician couldn't detect anything particularly wrong with him. As he grew older, he started to get very

he started playing soccer at four years of age, his parents, Denise and Darren, would constantly pull him off the field as he would struggle to breathe.

Finally, after a really bad episode, his parents called the ambulance and Jordan was admitted to The Children's Hospital at Westmead. Various tests

“Jordan was six years old and very scared – he thought he was going to die. We were in shock that his condition was so serious. He was discharged a few days before Christmas and we tried to make Christmas as happy as possible, but it was extremely difficult.”

breathless with exercise and turn blue around the mouth. Jordan's symptoms were attributed to asthma and croup and he was treated for both. But Jordan was always sick – and the older he got, the worse his symptoms became. When

followed – a barium swallow which showed a narrowing of his oesophagus; an echocardiograph which revealed all his outer heart defects; lung function tests; a bronchoscopy and endoscopy under general anaesthetic; and an MRI

scan also under general anaesthetic.

Soon after, doctors at The Children's Hospital at Westmead confirmed the diagnosis – Jordan had an extremely rare heart defect that only occurs in about one in five million people. His condition was very serious and he had to undergo heart surgery as soon as possible. On 17 January 2005, Jordan underwent the operation. It was a complex procedure, but successful.

Three years have gone by since his heart surgery and Jordan is now nine years old. As a souvenir from his ordeal, he sports a big scar that extends from his spine to under his left arm. He has residual tracheomalacia (floppy trachea) – but otherwise, is in good health. Jordan and his parents have learnt to handle some of his symptoms at home. For instance, when he gets the barking cough with a cold or flu, they know they need to give him medication and sit him upright to sleep. Jordan and his parents have also had counselling at the Hospital to help cope with everything he has gone through.

“Jordan loves doing things to help the Hospital,” says his Mum, Denise. “For the last two years, he was involved with the Woolworths Fresh Future Appeal and the George Gregan Foundation to help raise funds for The Children's Hospital at Westmead. It was like getting something positive for all the painful and scary things he had to endure.”

“Darren and I have had to watch our little boy go through some terrible procedures in his young life – and it's been heart wrenching. Without The Children's Hospital at Westmead, we wouldn't have Jordan, so we owe them his life. How does one repay that? From the highest medical professionals to the service staff, they were all kind, caring, supportive and went above and beyond the call of duty. If, in some small way, we can help the Hospital get much needed donations, we will do everything in our power to help. After all, what price is a child's life?” 🐾