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the  
children's  
hospital at Westmead

## Winter Appeal 2010

***“Matthew must have come into this world for a special reason. So you have to continue with your appeal and complete his story and raise as much money as possible to help sick children – it’s what he would have wanted... and it’s what we want for him so that he can rest in peace.”*** Kevin, father of three-year-old Matthew

This is a story about a young boy called Matthew who was born with a serious and rare craniofacial disorder. You may find some of the content upsetting, but it’s important that Matthew’s story is told as it helps to raise awareness of his condition and also demonstrates the breadth of care and support that the Hospital is able to provide for sick children and their families – thanks to the support of kind people like you.

Matthew’s tragic outcome is a rare occurrence at the Hospital, but the sad reality is that with some complex conditions, such as in Matthew’s case, things can take an unexpected turn despite the best medical care.

Matthew has touched the hearts of countless people. His loss has come as a deep shock to all of us at the Hospital, especially those who knew him as the delightful, happy child that he was.

When you read the following pages, you will see that no story better illustrates the value and urgency of your donations than that of Matthew and his family.

### Meet Matthew

Matthew was born on 25 November 2006 at Tamworth Hospital, close to his family home in Coonabarabran. After giving birth, Clara immediately passed out due to the effect of the anaesthetics and Kevin, Matthew’s father, was the first to see their baby.

***“The doctor brought Matthew to me and told me there was something wrong with our baby... She showed me his hands and in each hand, his four fingers were joined together like a web. She showed me his feet... and all five toes in each foot were joined together too.***

***“She mentioned the odd shape of his head, a cleft palate and some other problems, but I felt my brain shutting down and I couldn’t absorb anything. The shock was just too much.***

***“All I could understand was that something was seriously wrong with our baby. Beyond that, I just couldn’t think or talk. I knew I had to be strong for Clara, but I couldn’t bear to think of how she was going to feel when she woke up.”***

Clara eventually awoke to find her baby beside her. Too afraid to place the baby in Clara’s lap, Kevin stood by nervously, steeling himself for her reaction. Clara recalls:

***“The first time I saw my baby, his hands looked like mittens: four little fingers that were fused together and one tiny thumb. ‘What’s the matter with his fingers?’ was my first question.***

***“Then I held him in my arms and saw his head and webbed toes and everything else... and I was overwhelmed with a sense of sadness for my little boy.***

***“For so long I had dreamed of this day when I would hold my baby for the first time – and this was not at all how I had expected it to be.***

***“How could this happen? Why us? Why our baby?”***

After three days in intensive care, Matthew was transported via helicopter to The Children’s Hospital at Westmead and admitted to our Grace Centre for Newborn Care. With the help of our Genetics teams, Matthew’s condition was confirmed as Apert Syndrome, a craniofacial disorder involving abnormal growth of the skull and the face.

### **Matthew’s medical condition explained**

Put simply, when babies are born their skulls are made up of several separate bones – or plates – that allow the skull to grow as the brain grows. If you’ve ever held a newborn baby, you might have noticed the soft spot on the top of its head through which you feel like you could almost push your finger.

As a child’s brain grows very quickly in the first two years of life, almost doubling in size, so too does the skull to accommodate this growth. And when the head has finished growing, the seams of the skull bones fuse together and solidify. However, with Apert Syndrome, a number of these seams fuse too early, preventing the skull from growing any further. This affects the shape of the head but, more importantly, exerts pressure on the brain.

Alongside this potentially fatal problem, Matthew also had a series of other related problems – a cleft palate, fused fingers and toes, bowed thumbs, wide-set eyes, tall head and a very small and underdeveloped mid-face. Both his tear ducts were blocked, causing constant watering from his eyes. He had breathing problems and was found to have obstructive sleep apnoea.

At seven months, Matthew had to undergo his first major surgery, a procedure called Occipital Advancement. With the involvement of neuro and craniofacial surgeons at The Children’s Hospital at Westmead, his head was opened up and his skull cavity expanded to release some of the pressure and allow room for his brain to grow.

Matthew’s cleft palate meant that the roof of his mouth was not joined. At about 12 months, Matthew underwent a cleft palate repair to enable his palate to function normally.

Then there were his webbed hands to fix. Over the next few months, Matthew underwent a complicated series of hand surgeries to gradually separate his fused fingers, with skin grafting to enable them to look and function like normal fingers.

Matthew progressed well with his hand movements and his ‘new-found’ fingers.

***“Before Matthew’s hand surgery I said to the surgeon, ‘We don’t need him to be perfect. It’s alright if you can’t make his fingers normal like us. We just want him to have five fingers on each hand so he can make the most of his life.’***

***“But his doctors were so good. They made good fingers for Matthew.”***

By this point, Matthew had already been seen by more than 15 departments and operated on by six different surgeons. In the Cleft Palate Clinic alone, he had been seen by a team of speech pathologists, plastic surgeons, orthodontists, audiologists, nurses and ENT surgeons.





It costs about \$15,000 a day to run our Cleft Palate Clinic. So you can already start to see how important your gift today is to the children who need this service.

Over the next two years, Matthew's family made countless trips to the Hospital for his treatment and care. Procedures were undertaken to unblock his tear ducts to stop his eyes from constantly watering. He had his tonsils and some nose tissue removed to help with his breathing and sleep apnoea.

By the age of three, Matthew had endured six major operations and numerous minor procedures and had made over 50 visits to the Hospital, 12 of which involved admissions as an inpatient.

He had completed his initial round of treatments for the major functions critical to his growth and development, but he still had to visit the Hospital for regular check-ups to ensure that his progress remained on track. And incredibly, Matthew appeared to be quite advanced in many ways for a three-year-old. He talked, knew his alphabet and even sang songs.

### **A tragic turn of events**

Matthew had a routine follow-up appointment at The Children's Hospital at Westmead scheduled for 28 May 2010. He spent the day before his appointment in Sydney doing some of the things he had been longing to do for a long time.

He spent the entire day in the city, having a great time at the Sydney Aquarium and Wildlife Park. And later on, he and his family were treated to a delightful evening full of gifts and treats as the special guests of one of our generous supporters.

Unfortunately, the night ended with a tragic twist when Matthew's condition took a sudden turn for the worse. He collapsed and turned blue and was immediately rushed to the Hospital's Intensive Care Unit. He spent the next four days in Intensive Care while his medical team concentrated their combined skills and expertise to try and get him back on the road to recovery.

**But despite the team's best efforts, Matthew's condition deteriorated and he just could not be saved.**

We were all completely devastated when we heard the tragic news and couldn't even begin to imagine the depth of pain and grief that his parents, Kevin and Clara, must be feeling.

Niranjala, who had worked closely with Matthew's family in developing the fundraising appeal, went down to Intensive Care to see them later that morning.

*"I was gripped by their feelings of loss and despair," she said. "My heart ached unbearably and I stood by Matthew's bed watching helplessly as Kevin and Clara struggled to cope with the intensity of their grief.*

*"It seemed so unfair that any parent should have to go through the agony of losing a child, but this was the tragic reality. I felt completely speechless, unsure of what to do next, when Kevin took my hand and said imploringly:*

***"You won't stop Matthew's story, will you? You told his story so beautifully and shared it with so many people. Now you have to write to everyone and tell them how his journey has ended.***

***"When we drove to Sydney last week, we never thought we would be returning home without our Matthew... all this seems like a terrible dream.***



***“But it seems like he planned everything. He made sure he had the best day of his life from morning to night, until he collapsed – as if he knew he had to make the most of his last day.***

***“And if he had died two months ago, only a handful of people would have known that Matthew had been and gone. But he picked the right time to feature in the Hospital's appeal – as though he wanted his story to be told to make people aware and raise money to help other sick children.***

***“He must have come into this world for a special reason. So you have to continue with your appeal and complete his story and raise as much money as possible to help sick children – it's what he would have wanted... and it's what we want for him so that he can rest in peace.”***

Niranjala was truly inspired by Kevin's sincere words and his compassion in the face of such an unexpected tragedy – and so are we. It's comforting to know that we have unwittingly played such an important part in their lives by featuring Matthew in our appeal.

In spite of their sudden and tragic loss, Matthew's parents have shown great compassion. And their only consolation is the thought that their precious child's life has served a purpose – that his story will help raise money that could improve the chances of survival for other sick children and perhaps spare other parents the heartbreak of losing a child.

Matthew's story shows there is a lot more work to be done to investigate the causes and effects of serious childhood illnesses and perhaps even find a cure to be able to save children like Matthew. With your help, we can achieve this goal.

We want to be able to tell Kevin and Clara that Matthew's short life and his suffering have not been in vain – and that we have received an overwhelming response from supporters who have responded generously to our appeal with Matthew's story. This is why your gift today is so important.

**No story better illustrates the value and urgency of your donations than that of Matthew.**

So please, if you can, give us a gift today.

**CLICK HERE  
to make an online donation today!**

Your donation of \$2 or over is tax deductible.

