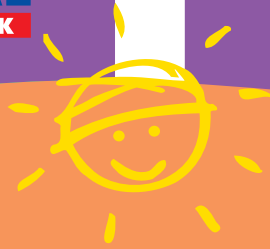


june 2006



## NaoMi fACEs hER FiNaL opERAtion

**W**hen Rebecca and Luke welcomed their first child into the world, the relief of having a trouble-free birth was overshadowed by emotions of fear and shock. Their baby girl Naomi was born blue. She wasn't getting enough oxygen and doctors at their local hospital in Port Macquarie immediately knew they had to act quickly to save her life.

Within a few hours, Luke was flying to Sydney Children's Hospital Randwick with his baby in a Careflight helicopter where she was admitted to the Intensive Care Unit and placed on life support. That night, Rebecca was driven to Sydney to join her family.

Naomi was diagnosed with a complex heart condition involving the ventricles and main arteries coming from the heart, preventing her from receiving enough oxygen into her blood stream.

Her first operation at five days old was a procedure to enable blood from the lungs to pump to her heart in order for her to grow big enough for the next operations.

"It was horrible; the first days of our life as a family were spent by her bedside in intensive care. Being far from home, the hospital staff became our surrogate family and supported us as much as possible. It was the hardest time of our lives." said Rebecca.

After seventeen gruelling days in hospital Naomi had stabilised and Luke and Rebecca were able to take Naomi home. However, it was never far from their thoughts that Naomi was a very fragile little girl.

"There were times, especially in the early days that I would stay awake watching her sleep, frightened that her heart may stop at any point. She grew up knowing that she wasn't able to do the same physical activities as other kids, and knows her limits. She needed further vital operations before she could begin to live a normal life" said Rebecca.

Dr Owen Jones, Naomi's cardiologist had consultations with Naomi at the outreach clinic at Coffs Harbour every three months to monitor her progress and medication.

Over the course of the next five years, brave Naomi had three major heart operations at different stages of her growth to gradually enable her heart to function more normally.

*"We never lost our confidence in Dr Jones and his cardiology team. They saved her life when she was one day old and we know they will do their best for Naomi no matter what"*



## LETTER FROM LES WHITE

Dear Friends and Supporters,

There is convincing evidence that the complexity of our specialist services for the children of NSW continues to rise. In many specialties there is a constant expansion of the expert knowledge, available technology and the capacity to treat, and possibly cure conditions, with ever improving outcomes. The lead story on this occasion features Naomi, a 5-year-old child from Port Macquarie who has already required a series of operations to repair a complex congenital cardiac condition. This example highlights two key principles.

Firstly, complex and ongoing care requires not only expert cardiologists and cardiac surgeons but a comprehensive team of health care professionals who share both the expertise and commitment to provide the best available care. The team further extends beyond our Cardiac Services team to anaesthesia, intensive care and recovery ward as well as a range of nursing and allied health professionals.

Secondly, the Thompson family exemplifies our historic and continuing leadership in the care of children from rural and regional NSW. This requires clinical networks and mutually supportive partnerships with our colleagues in regional centres. It further exemplifies partnership with families and the resources available to accommodate and care for them, particularly during periods of family disruption when they need to spend time at the "Randwick hub".

May I take this opportunity to thank not only my dedicated and hardworking colleagues but, very importantly, our friends and supporters whose advocacy, enthusiasm and financial support make our commitment possible.

Thank you and best wishes,  
Professor Les White, Executive Director  
Sydney Children's Hospital

Les with ????

*"Complex and ongoing care requires not only expert cardiologists and cardiac surgeons but a comprehensive team of health care professionals who share both the expertise and commitment to provide the best available care."*

## Naomi's Story cont...

"With every operation she amazed us by her bravery. We are so proud of her" said Rebecca.

Her most recent operation at five years old was the most nerve-racking for Rebecca and Luke and it will hopefully be the final stage in her treatment. Her heart had grown strong enough to endure a complex operation to re-direct the blood coming back from her body directly to her lungs. The operation took five hours and Luke and Rebecca were prepared that the first 24 hours were the most critical.

"We were so close to finally achieving a positive outcome for Naomi, but we were prepared for the worse when she did go

into the operation. We never lost our confidence in Dr Jones and his cardiology team. They saved her life when she was one day old and we know they will do their best for Naomi no matter what" said Rebecca.

Brave Naomi impressed the doctors by her speedy recovery immediately after the operation. Only three days after the surgery she was able to talk to her relieved parents. Now Naomi is resting up in the cardiology ward but excited about getting back home. This bright little girl with a sunny smile has much to look forward to.

# Jamila

## StAnDs TaLL AGaiN

**N**o one ever imagined that when Jamila had some days off school with a sore tummy that she was suffering from anything worse than the flu. But she looked pale, had weak legs and her back was hunched over.

When she fell down and couldn't get up again, her mum Lorraine didn't take any chances and took her to the local doctor and from there she was referred to the local hospital.

The hospital gave her an MRI scan which showed that she had severe swelling in her spinal cord. An ambulance drove Jamila and her worried mum to Sydney Children's Hospital Randwick to be immediately seen by a paediatric neurologist. It was then that neurologist Dr Annie Bye told Lorraine that Jamila had Acute Disseminated Encephalomyelitis (ADEM) – a disorder of the brain and spinal cord that can cause weakness of arms and legs and may interfere with bladder control. She explained that only 4 or 5 children are admitted to the hospital with the illness each year and it may occur following a virus.

Jamila was immediately admitted to the Intensive Care Unit and given high dose of steroids, which the doctors hoped would hasten recovery. There was concern that the illness would begin to affect the muscles used for breathing and that Jamila might require life support.

"Jamila knew what was happening to her and the doctors helped her to feel less scared, but it was very frightening for everyone" said Lorraine.

Jamila's legs were paralysed and the arms became weaker over the following days but Jamila was still able to move them a little. Fortunately she did not require life support and was able to breathe on her own.

It was an incredibly agonising time for everyone in the family, as they feared that Jamila may never walk again. However, day-by-day over seven weeks on steroids, Jamila started getting better. With the help of physiotherapists and rehabilitation, she was able to take her first steps and recover some movement in her body.

Lorraine finally started feeling more relaxed when Jamila began to walk and stand on her own. Life would indeed get better for Jamila.

"It was really wonderful that Jamila responded so well to the treatment and rehabilitation. All through the time in hospital Jamila was really brave. For most of the time she had a beautiful big smile on her face" said Dr Annie Bye.

Now seven months after the hospital admission Jamila has started to run again. She is back at school, and doctors are hoping for further improvements.

*"It was wonderful that Jamila responded so well to the treatment and rehabilitation. All through the time in hospital Jamila was really brave. For most of the time she had a beautiful big smile on her face"*



# Did you know...

## stAYiNG WeLL oVEr WiNTEr

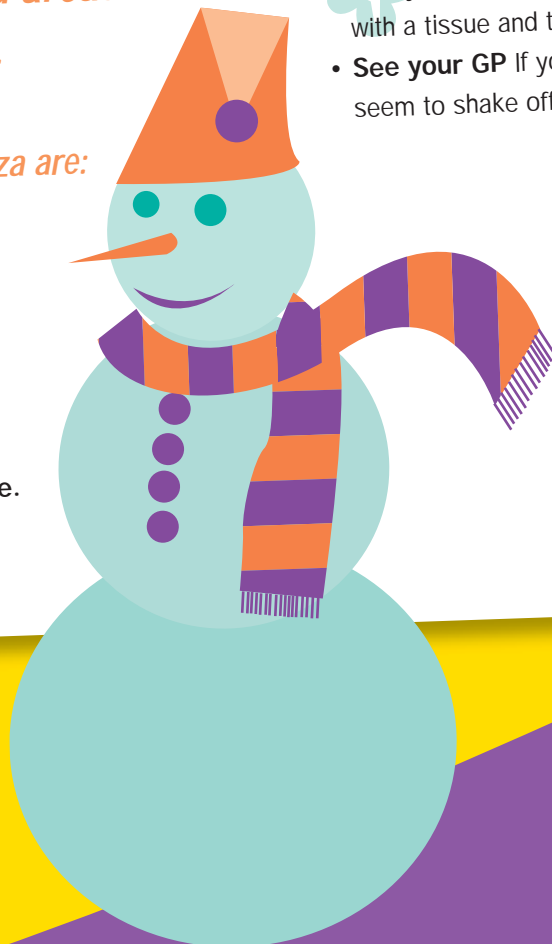
*As we all know, with the winter months come more respiratory illnesses, such as the common cold and influenza. These can be spread from person to person when an infected person sneezes or coughs and are easier to catch in crowded areas or confined spaces.*

*Symptoms of influenza are:*

- Fever
- Headache
- Muscle and joint pain
- Feeling tired
- Sore throat
- Cough
- Runny or stuffy nose
- Often extreme fatigue.

*YOU CAN MINIMISE YOUR CHANCES OF YOU GETTING SICK, BY FOLLOWING THESE SIMPLE STEPS:*

- **Get a flu vaccination.** Vaccination is an effective protection against influenza infection. Speak to your GP about influenza vaccination before winter each year. All adults over 65 and anyone over 6 months with chronic diseases affecting the heart, lungs, or that require regular medical check-ups are especially recommended to have the vaccine.
- **Stay at home.** If you or your family are unwell, avoid crowded and confined places if possible
- **Wash your hands.** Make sure you wash your hands regularly to reduce the chance of spreading infection.
- **Cover it!** When you cough and sneeze, make sure you cover your nose and mouth with a tissue and throw it in the bin.
- **See your GP** If you have a high fever, or can't seem to shake off your illness, see your GP.



# JAKEb GroWwS StRoNGer EACh dAY



*"People ask me how I can be happy? I answer that the day Jakeb was born; he had a 30% chance of survival. Now he is six months old I know he will get better. I can't thank Sydney Children's Hospital enough"*

**W**hen Marinel was pregnant with her third son Jakeb, she couldn't shake the feeling that something was wrong. She felt more relieved when it was time for an ultrasound check on the baby at 19 weeks.

It was during this check that Marinel's fears proved to be correct – Marinel and Eddie were told that their baby had a diaphragmatic hernia. As he was growing in the uterus, the left side of the diaphragm didn't grow to divide the contents of his stomach from his chest which meant that Jakeb's liver, spleen, small intestines and stomach were all in his chest. Doctors gave Marinel and Eddie the heartbreaking news – their baby had a 50% chance of being able to be ventilated by life support machines once he was born.

"We were warned that the baby would be very sick and that immediately after birth he would need to go straight to the Intensive Care Unit at Sydney Children's Hospital. We met the doctors and visited the ICU before Jakeb was born so we knew what to expect" said Marinel.

As planned, when Jakeb was born in the adjacent Royal Women's Hospital he was taken immediately to ICU and ventilated. After two weeks Jakeb had an operation to

put a patch along where the diaphragm divides the chest and stomach regions to encourage his diaphragm to grow.

However, a few weeks later, Jakeb's diaphragm opened up again and the family was back in ICU preparing for his second operation. Despite the best hopes that this time his diaphragm would begin to work properly, it was bitterly disappointing that only one week after the second operation x-rays showed that his diaphragm had opened up again.

"We were so disappointed that Jakeb's surgery just wasn't working but the doctors reassured us that Jakeb's chances of a success would be higher if they waited until Jakeb was six kilograms" said Marinel.

Now at four kilograms, Jakeb is gaining weight each day, much to everyone's delight.

Looking back, Marinel acknowledges the hardship of having such a sick baby, but finds solace that Jakeb received the very best care.

"People ask me how I can be happy? I answer that the day Jakeb was born; he had a 30% chance of survival. Now he is six months old I know he will get better. I can't thank Sydney Children's Hospital enough" said Marinel.

# UPDATES... HOW ARE THEY NOW



Age ? years



Age ? years

**Y**ou might remember Liam Watson who was featured in our September newsletter last year. Three-year-old Liam was battling leukaemia and had just recovered from a rare reaction to his leukaemia treatment which paralysed his body and left him temporarily unable to walk. After stopping his treatment and receiving regular physiotherapy, Liam regained his ability to move and was ready to face his final two weeks of chemotherapy.

Liam has come a long way since completing his chemotherapy treatment and he has been back at home taking maintenance drugs for the past five months and feeling well again.

His doctor, Professor Marshall, still monitors his progress; however it's finally back to a normal life at home for Liam.

"Liam has come so far. He started preschool this year, his hair has grown back and the physiotherapy sessions have helped him regain full movement in his body. He's doing great. We can't thank the hospital enough - they are miracle workers" said Liam's delighted mum, Renee.



- Allens Arthur Robinson
- Foote Cone and Belding
- SBA Design

# YES!

## i would like to help sick kids



Please find enclosed my donation of: (please circle)

\$50      \$75      \$125      \$500      or \$ \_\_\_\_\_

Enclosed is my cheque or money order made payable to Sydney Children's Hospital Foundation, or please debit my credit card details below.

Bankcard       Mastercard       Visa       Amex       Diners

Card Number                        

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We respect your privacy and do not give your name and address to any other charity or business. Donations are tax deductible. Please return this coupon and your donation to Sydney Children's Hospital Foundation, Locked Bag 5, Randwick, NSW 2031 and we will forward a receipt. Sydney Children's Hospital Foundation ABN 72 003 073 185. Telephone (02) 9382 1188 email schfoundation@sesiahs.health.nsw.gov.au website www.sch.edu.au. Sydney Children's Hospital Foundation would like to thank those companies who made the production of this newsletter possible. Your generosity and commitment is greatly appreciated. Your name will be placed on our mailing list and you will, from time to time, be mailed fundraising and health information such as this newsletter, invitations to events, Christmas card catalogues, etc. If you do not wish to receive this information or do not want your name to be placed on this list, please tick this box