

Winter Appeal 2009



An extraordinary story about a little girl who overcame the greatest of odds

“From a physically disabled baby to a confident, ambitious young lady... Rae has undergone a miraculous transformation and now has the world at her two very able feet. Rae’s abilities are such that we often forget she has a disability.” Lian, mother of 12-year-old Rae.

Rae Anderson is no ordinary girl. Born with Cerebral Palsy, Rae is a true testament to the care and dedication of her healthcare team at The Children's Hospital at Westmead and a source of hope and inspiration to anyone who meets her. When Rae's medical condition was diagnosed eleven years ago, her parents had very little hope that their baby girl would be able to walk or use her left hand functionally, let alone lead a normal life.



“We were totally devastated to learn that our little girl had Cerebral Palsy,” recalls Lian. ***“Looking at our precious baby who was blissfully unaware that there was anything wrong with her, we knew we would do anything to ensure that she could have as normal a life as possible. We had a long journey ahead... and we would take it one step at a time.”***

Rae has journeyed through most of her childhood and schooling years coping with Botulinum Toxin (Botox) therapy, numerous surgical procedures, wheelchairs, crutches, plaster casts, a hip plate, surgical foot supports, and limited mobility in the left side of her body. Despite the debilitating effects of her condition, the combined treatment over many years from her various doctors, surgeons, physiotherapists, occupational therapists, rehabilitation specialists and orthopaedic specialists have transformed her life.

Today, Rae is a charismatic twelve-year-old. Strong and confident, she has exceptionally good health and enjoys a variety of outdoor activities. She has managed to push the boundaries and experience far more than the average, able-bodied girl of her age. Rae was able to achieve this with the help of the amazing medical talents and technology available at the Hospital, and also with the tremendous support of our compassionate donors who enable us to continue to see the progress in children suffering from debilitating illnesses.

In the difficult and volatile financial climate that we live in today, it's all the more important that we are able to carry on our vital work. **That's why we need your help to raise \$300,000 before 30 June, the end of this financial year, to help children like Rae who suffer from conditions like Cerebral Palsy.** Your donation today is so important to ensure that we can continue to provide the highest level of care to every sick child who comes through our doors.

Rae has certainly come a very long way. Her story is not only inspiring, but also an outstanding reflection of the extraordinary work done every day at The Children's Hospital at Westmead.

Rae was born in February 1997. Her parents, Lian and Russell, were ecstatic at the birth of their beautiful baby girl who looked perfect and healthy in every way – and like most families with a newborn, many happy months went by. When Rae was about eight months old and started playing with toys, her parents noticed that she wouldn't reach out for anything with her left hand or hold anything with both hands. They thought it was just a babyish quirk that would pass. But as she approached twelve months of age, it became more obvious that Rae was always holding her left hand in a fist tightly against her chest, with her elbow bent at a 45 degree angle. It was then that they decided to consult their family doctor, who referred them to a Paediatrician.



On examining Rae, the Paediatrician discovered that her left leg was turned in and was actually shorter in length than her right leg. After conducting brain scans, the shocking diagnosis was made – Rae had Cerebral Palsy.

Cerebral Palsy refers to a variety of conditions where there is a disorder of movement or posture caused by damage to areas of the brain that control the muscles. As a result, the muscles and joints in the limbs can become stiff and lead to bone deformities. Unfortunately, Cerebral Palsy is a permanent condition for which there is no cure and it is the most common cause of disability in children. Rae had a type of Cerebral Palsy known as Spastic Hemiplegia and it was affecting the left side of her body.

Rae soon commenced consultations with physiotherapists and occupational therapists close to home at the Gosford District Hospital. It was important to stretch her muscles in the correct alignment, improve her mobility and help her to learn to walk as well as possible. This was to become the first step in a long and arduous journey for little Rae and her family.

Soon, the effects of Rae's condition became more evident. She couldn't crawl and would only shuffle on her bottom with her left hand in a fist and her right hand supporting her weight. Rae didn't attempt to walk until she was 15 months old and, over time, her leg twisted inward and she walked on the outer border of her inwardly bent foot. She was unstable when walking and would constantly trip and fall over.

When Rae was three years old, she commenced serial castings on her left leg in combination with physiotherapy and occupational therapy. At the same time, it was evident that Rae needed specialised intervention to proceed to a higher level in her treatment and she was referred to the Physical Disability Clinic within the Rehabilitation Department at The Children's Hospital at Westmead.



Rae was accepted into the Hospital's Upper Limb Botox Study led by Rehabilitation Specialist, Dr Mary-Clare Waugh, during which she received Botox injections into her left arm. Rae also attended the Botox Clinic for injections into her leg to try and correct her foot posturing. She was trialled with a solid ankle foot orthosis (AFO) to support her hind foot and ankle, in order to minimise her tripping episodes. She continued with serial castings to correct some of her foot problems.

Such complex treatments for a little girl who had already been through so much – but unfortunately, it didn't end there.

By the time she was five years old, more significant changes had developed in her left foot. Rae was able to walk independently and was using a hinged AFO as much as possible. She could use her left arm and hand independently and functionally up to a point. A year later, Rae underwent surgery to try to relieve her foot problems; unfortunately, the procedure had little benefit for her.



At seven years of age, Rae was referred to the Hospital's Senior Orthopaedic Specialist, Dr Matthias Axt, with the view of further surgery. Dr Axt observed an internal rotation of her left leg during walking and an increased internal rotation of her left hip. She showed overactivity of some muscles and weakness in others and also had reduced strength and function of her left fingers. Dr Axt recommended Botox injections in her left hand and some more surgery to her left leg within the next six months to prevent increasing deformities.

In April 2005, Dr Axt performed multilevel surgery to Rae's left leg and an angulated blade plate was inserted in her left hip joint. The surgical procedure was combined with courses of Botox injections to her hand, arm and shoulder. The surgery was a success. Rae went home with her leg in plaster and was wheelchair bound for four weeks. She attended follow up treatments and went from wearing a full cast, to a half cast, to an AFO, with a shoe rise in her left shoe.



This surgery performed by Dr Axt made a miraculous change to Rae's life and she began showing many remarkable improvements. When reviewed a year later, by Dr Axt and Dr Stephen O'Flaherty, Head of the Hospital's Rehabilitation Department, they both noted that Rae's foot was well balanced and she was able to walk and run symmetrically. She could use her left hand functionally and she experienced no restriction in her daily activities. At this time, Rae was nine years old.

"Something I will never forget is the look of sheer delight on the face of Dr Axt and his staff at the progress Rae had made," says Lian. "When Dr Axt said to Rae, "Young lady, you do not belong in the Physical Disability Clinic anymore" and commented on her near perfect foot strike and gait, I had tears in my eyes. You are always made to feel like the most important person in the world when you are with Dr Axt and his staff."

For so many years, Rae and her family had to deal with the ups and downs of a relentless treatment regime – countless examinations, treatments and procedures to ensure she had the best possible chance for the future. Our staff specialists are so often at the cutting edge of medical technology and I am amazed by their committed efforts that so often result in miraculous outcomes, like that of Rae's. They transform the lives of children who might otherwise have had little chance of enjoying childhood experiences, realising their life's potential or fulfilling their dreams.



Can you imagine the outcome if Rae and other children like her did not have the access to this cutting edge treatment?

We need to raise \$300,000 by 30 June this year, to help fund vital and life-saving work like that of Dr Axt and Dr O'Flaherty. Your donation today will ensure that we continue to provide the best treatments available and see the progress in children like Rae who suffer from Cerebral Palsy and other devastating illnesses.

In May 2007, Rae underwent surgery to remove the hip plate and screw that had been inserted into her upper leg two years earlier. She was also given another round of Botox treatment to improve her ability to extend her left elbow and enable rotational movement of her left hand.

At ten years of age, Rae was functioning just like any other healthy child of her age, without the use of any technical devices. Apart from a very slight limp on her left side, she had full range motion of her left hip and knee. Her left leg was well aligned and she had good mobility in her left hand.

When examined in August last year by Dr O'Flaherty, Rae's walk remained smooth and balanced and her left hand hung nicely by her side. She was coping well at school. She had neat handwriting, the only problems being that her writing was slow and she held her left hand in a fist position below her writing hand to balance herself. At Dr O'Flaherty's recommendation, Rae continues to see an occupational therapist for treatment to her left hand and has completed writing analysis to gauge her writing speed and endurance to help keep up with her schooling.

“The majority of people who meet Rae and many who have known Rae for some time are shocked to learn she has Cerebral Palsy,” says Lian. “Rae’s life has been changed so dramatically by the surgical genius of Dr Matthias Axt as well as the Botox therapy by Dr Stephen O’Flaherty and Dr Mary-Clare Waugh which, with every administration, made a significant difference to Rae’s range of movement.”

“Thank you does not seem sufficient to convey our gratitude to everyone who played a part in Rae’s transformation. We have nothing but praise and the utmost respect for the wonderful staff of The Children’s Hospital at Westmead and will be eternally grateful to them. They truly are our nation’s unsung heroes.”

Rae’s determination and “don’t tell me no” attitude have seen her achieve anything she has set out to do. On 5 December 2008, Rae reached a remarkable milestone when she was elected Sports Captain of Terrigal Primary School for 2009. A special achievement for any girl her age – but for Rae, after all the physical handicaps she had battled through since she was just a baby, this was a truly exceptional honour. It brought tears to the eyes of her proud parents, friends and school teachers.

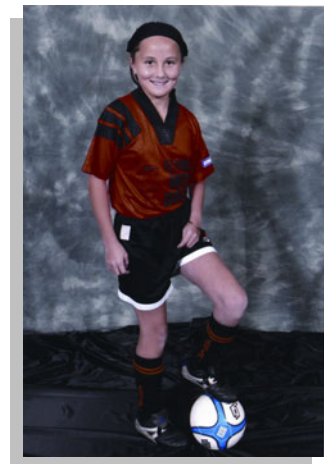
That very same day, Rae’s parents wrote to Dr O’Flaherty: ***“Today, Rae reached another milestone that not only made us proud of her and her determination and tenacity, but one that is also a testament to the care and work that you, Dr Axt and all the staff at the Hospital provide. For Rae to progress from operations, wheelchairs and crutches in her earlier years to School Sports Captain has blown us away and we just had to let you know.”***

Rae’s heart-warming story is not only a testament to the extraordinary work carried out every day at The Children’s Hospital at Westmead, but also demonstrates the dramatic difference that your support makes to the lives of children with complex medical problems.

Your donation really has the power to change lives.

Please give generously to our Winter Appeal today. With every donation you make, more children like Rae can overcome the debilitating effects of their illnesses and be given the opportunity to turn their lives around.

On behalf of Rae’s family, the staff of The Children’s Hospital at Westmead and the countless sick children and their families who will benefit from your generosity, we thank you.



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