September 2012

This summer saw sport and celebration at London 2012 surpass everyone's expectations and the shuktara residents in Calcutta were equally enamoured with what was going on, particularly of course, with the Paralympics.

They watched in awe and amazement as professional dancer David Toole was magically lifted and flew about the stadium during the opening ceremony. Born with legs that were crossed, a decision was made to have them amputated at 18 months, to give him easier mobility. As a couple of the shuktara boys and girls spend their time moving around with legs that don't work, it was inspiring for me to see what can be achieved and for them to see how others with limited mobility can do so much for themselves as well.

We have never pushed any of them, but have allowed them to grow with their disability and encouraged them to do as much or as little as they want – Sumon can move across the floor faster than most of us with working legs.

At the same time as the Paralympics, Tuesday September 4th, 2012, was hailed as the first annual World Cerebral Palsy Day and I thought I would share with you the stories of the children with cerebral palsy who live at shuktara, showing us that like most things in life, there is uniqueness about each one of us.

British comedian Francesca Martinez, who has cerebral palsy, prefers to describe herself as "wobbly", probably due, to the obvious CP stereotype of being unable to control movements (as with Ashok here at shuktara – who is also "wobbly"). But cerebral palsy comes in different forms from slight clumsiness at the mild end of the spectrum to impairments so severe that they render coordinated movement virtually impossible. It is unlikely that any of the shuktara boys or girls will ever be able to compete in sitting volleyball or wheelchair tennis, but their own individual achievements are just as valuable and important to them as winning gold in London.

Meet our CP boys and girls - Sumon, Raju, Bablu, Ashok, Lali, Prity and Ratan



Sumon Goswamy was found on Howrah Station, alone, unable to walk, covered in dirt and with a 10 rupee note tied in a handkerchief to his wrist. We were told about him by a French organization, and they immediately brought him to us. Sumon was terrified. His older brother had taken him in a taxi and just left him on the platform. For many months Sumon would uncontrollably urinate whenever anyone went near him and it took him a long time to be settled. He still loves going to school and even though he is probably 16 or 17 years old now, they are happy, for the time being, to keep him. Sumon has learning disabilities and little use of his legs, but that does not stop him from being our very own Usain Bolt on the floors of the shuktara house.



Raju Das was born on the pavement at Kalighat and was living with his grandmother. His mother had died and his father just disappeared. His grandmother and he lived, ate and slept on the pavement and she would ask people to take Raju away, somewhere safe, away from the busy road. One day, friends of mine happened to pass and they asked her if she really meant it – because shuktara would take him. He came with them and was immediately at home. His grandmother would visit every Saturday, until one Saturday morning we received news that she had died. He visited her for the last time. Raju's cerebral palsy affects only one of his legs.



Bablu Lal, is without doubt the oldest shuktara resident. He remembers nothing of his life before being institutionalized in Missionary of Charity homes, where he was moved around for years. During a visit to one of these centres outside Calcutta we met Bablu who asked us if we would take him. We said we would get back to the organization about this – but two days later he was delivered in a van and left at the shuktara home, with a note from the Brothers. Bablu is a real talker, with a stock list of phrases that he uses. His CP affects his legs badly, they are permanently bent at the knees, which cause him pain in his lower back, but it does not stop him from being very active and helpful around the house. He has a daily routine of washing his clothes, bathing and cleaning the floors of the house.



Ashok Chettri was left as a new born baby outside a Missionaries of Charity home in the center of Calcutta by his mother. He was then moved around different institutions until being brought to us by an Irish nurse who was working in a "home for the mentally ill" in Calcutta. She noticed Ashok and was aware that he had been wrongly diagnosed. In fact Ashok, an intelligent young man with cerebral palsy had been wrongly diagnosed all his life. He had been crying out to people that there was nothing wrong with him and finally someone listened. Ashok cannot speak but he has full understanding of Hindi, Bengali and English. His cerebral palsy affects all his movements, but doesn't restrict him from anything at all. He is totally independent and refuses any kind of help. Ashok is standing next to me as I write this and I have asked him if he has a message or anything he wants to tell everyone. His response after hearing what I have already written is - "I want to get married - but it is a secret, don't tell any of the other boys in the house"



Lali Khatoon is about 14 years old. Soon after we had decided to start a home for girls, Pappu was informed about two girls in a shelter home, both with disabilities who had no family to care for them and who needed a permanent home. This was exactly why we started shuktara in the first place. One of the little girls was Tamina – the other was Lali! We took them both. Lali was found alone in the centre of Calcutta by this particular organization, but they only give temporary accommodation. Her mother had disappeared and her father, a rag-picker, did not want to keep her. The organization kept her for a short period along with Tamina, until Pappu was able to bring her to shuktara. Tamina came first and Pappu returned the next day for Lali. Lali is hard of hearing and has very limited speech. Her arms and hands are affected by cerebral palsy, but this does not stop her from doing beautiful needlework and she is very determined in everything she does.



Prity Kundan was also left by her family in the Kalighat area of Calcutta. It appears that they had tried to have some surgery done on her legs, to help her walk. Probably unaware that she had cerebral palsy, we suspect that they were told that surgery would cure her. Prity will never be able to walk – CP affects both her legs and arms but she is able to lift her arms slightly. She is a highly intelligent little girl, she knows what she wants and she knows how to get it. She is doing very well in REACH cerebral palsy unit and studies English and Bengali at home with a tutor. Her favourite occupation at the moment is her sewing class – using her fingers and her teeth, she is able to complete given work and takes great pride in her accomplishments.



Ratan came to us in February and you will remember him from my last newsletter. He is a classic picture of a child with severe cerebral palsy just thrown away and neglected by a society that does not care. He was also left at Kalighat and moved around the city by the police, until he was taken to a home that had run out of funds. Here he was kept in a darkened room alone and occasionally force fed. When we were alerted to his condition he was already severely malnourished and our concern was that he could die. But Ratan was meant to be here with us. He has enriched all of our lives and his has changed forever. Ratan is deaf, non-verbal, doubly incontinent and has very little movement on his right side; however his left arm and leg are stronger.

Many children in Calcutta and around the world are left alone and abandoned by their families or through their own choice - run away from their home. We all know about street children and the lives that they live. I started shuktara because to live on the street with a disability is almost impossible. Most of our children would not have survived — Ratan and Sumon would have died and if they had not they would have been dumped in a Government Home, where they would have been alone and unloved. It is almost unbearable to think of the numbers of children and young adults in this situation today. We have taken the responsibility to help a few — we can do no more than that. And we have only been able to do it because of your generosity. Thank you.



SANJAY & RATAN

"Anyone can become disabled - the fact is, we will always be people first, with things we can and can't do second. I think everyone in life has their own 'disability' - something that challenges them - whether it is visible or not" - Francesca Martinez