

John*

Zaina gently tends her only child, John, who has hydrocephalus. His head is double the size that it should be. John's father left Zaina when she was pregnant so it is up to her alone to care for and provide for her son.

The term hydrocephalus stems from the Greek word "hydro" (meaning water) and "cephalus" (head). Often known as 'water on the brain', the water is actually a fluid that surrounds the brain and spinal cord. Events such as damage to local blood supply or infection (such as rubella) are believed to affect the baby's development before birth (congenital). Hydrocephalus can also be acquired through head injury or infection (such as bacterial meningitis) for instance.

"My pregnancy was not good," 22 year old Zaina explains, "I was sick all the time and I got chicken

pox." Shortly before John was due, an ultrasound showed that he was in breech position. The health care workers told Zaina that the baby would turn the right way round before the birth and so she should not worry.

The labour began at home in Dar es Salaam but when it did not progress, Zaina's parents borrowed money to pay for a taxi to take their daughter to hospital. When they arrived at the clinic, one foot was already presented, protruding from Zaina's body but there were no doctors available. "The nurses tried to find the other foot and they pulled him out feet first. After the birth, John didn't cry so I started to worry," Zaina recalls.

Once he was home, Zaina felt something was wrong but did not know what. He was six months old when she noticed his head starting to grow. "I



cried all the time seeing his head like that, I just didn't know what to do. Why did this happen to my child?" Local health workers were unable to make a diagnosis so a friend, whose child had been treated at CCBRT, told her to bring John to the disability hospital.

Dr Stan Kinsch, Orthopaedic Surgeon at CCBRT explains, "To avoid brain damage in cases of hydrocephalus, it is important to seek medical treatment at the earliest sign of any symptom to stop the build up of pressure in the brain. If hydrocephalus is recognised and treated very quickly, it is possible to avoid brain injury and resultant disabilities."

Now eight months old, the two month delay in accessing the right medical treatment for John could be critical in terms of the levels of disabilities he will suffer.

"During surgery we insert a shunt which is like a plastic tube into the head to drain the excess fluid from the head to the abdomen where it can be absorbed by the body. It is impossible to return the head size to normal size but it is possible to stop it growing anymore," explains Dr Kinsch.



The shunt and drain are likely to remain inside John for the rest of his life and the equipment may need replacing if it malfunctions or becomes infected. He will need lifelong follow up and at any sign of fever John must be quickly seen by a doctor.

Only time will tell the full extent of any damage to John's brain and any disabilities he may suffer but these could range from learning difficulties and incontinence to blindness or paralysis. Zaina is relieved that John is receiving medical treatment now. "Although I worry for his future, I am happy that I found a place that could see what the problem was and do something about it."



*Ngeni**

"When Ngeni was born, I was so scared when I saw her. Why has this happened I asked myself?" Ngeni's mother, Zuhura, recalls the moment her baby was born and seeing her face for the first time. Ngeni was born with a cleft lip and her mouth was misshapen. The nurses at the health centre in a village near Bagamoyo tried to reassure Zuhura that the abnormality could be repaired.

Abandoned by her husband, Zuhura lives alone and grows vegetables to feed her family of four children. When she took Ngeni home to her village, the baby was not welcomed. "People told me that a spell had been put on Ngeni by a witchdoctor and that she would always be like this. I didn't know what to believe."

She was referred to CCBRT and, although still sceptical, she came for an appointment where she

was shown pictures of babies before and after their cleft lip operations. “At that point, I knew it would be OK to let the doctors operate on Ngeni. I knew I had to do something as it was very hard to feed Ngeni. She was able to drink milk but when I tried to give her porridge it just came out through her nose and she needed to put on weight.” Talking to the other mothers on the ward with children in a similar situation also gave Zuhura confidence.

Just 24 hours after the operation, Zuhura can hardly believe the extraordinary alteration in her daughter. “She has changed into a beautiful child before my eyes, almost overnight. I just didn’t think she could be so changed, I’m very happy. I will take my daughter home and show those people that it is not witchcraft. Her disability was just something that happened and it can be solved. She will now be able to live a normal life and go to school without people pointing at her.”



*Stella**

Nine year old Stella quietly sits on her hospital bed in the orthopaedic ward at CCBRT’s disability hospital. One leg has an external fixator attached, the other is in open cast. Stella is fortunate to still have both of her legs and has just had major surgery to save them. She had an infection, called osteomyelitis, which was so severe that the thinned out bones broke after a minor injury. Osteomyelitis is an infection of the bone marrow and surrounding bone caused by bacteria and which could have started through the blood, through an inoculation or through injury. The family has no idea how or where the infection began.

Her mother, Saida, reveals, “For nearly two months, Stella was crying all the time. She had a fever and if



I touched her legs she cried out in pain. She stopped walking, even refusing to walk to school and just sat in the house all day. We did not know what was wrong. The doctors treated the fever but could not tell us what the problem was.”

“We call this a ‘disease of the poor’” explains CCBRT Orthopaedic Surgeon Dr Luijisyo. “It is only really seen in the developing world these days. It is a notorious infection and the presentation is confusing making a diagnosis difficult for a general doctor, many of whom put it down to malaria because of the resultant fever. Stella had such a

severe infection in her bone marrow that both her tibias were broken. It is unusual to see it in both legs simultaneously.”

In the operating theatre, the infected tissue and the dead bone were removed. Plaster casts could not be used to fix the fractures as the internal wound needs to heal first so an external fixator was attached to keep the bone straight. Dr Luijisyo is optimistic about Stella’s prognosis, “She is lucky that her family brought her to see us. If it had been much later, it may have been necessary to amputate both legs.”



*Terra**

Holding tightly to the support bars, Terra unsteadily moves one leg in front of the other. To see a four year old walking may not be remarkable in itself, but this four year old is standing upright for the first time in her life and taking her first cautious steps on two prosthetic limbs made at CCBRT’s orthopaedic workshop. To see Terra walking is something her family never thought would be possible.

Terra had severe malaria when she was two months old. Her father, Boniface, a farmer from Mwanza, says that after the treatment for malaria, Terra developed gangrene in both legs and, in order to save her life from the infection, the local hospital had to amputate them at the knee.



Although the hospital near to their home was capable of making prosthetic limbs, the family received a letter explaining that they could not make any prosthetics because there was no money left for materials. So Terra was referred to CCBRT. But the family of five is extremely poor, living on just 4,000 Tanzanian shillings a week (just over two euro) from selling any corn, maize and rice surplus to the family's needs. It took Boniface many weeks to save up the required transport money to bring himself and Terra to Dar es Salaam to seek treatment.

Keeping a watchful eye on his daughter, Boniface says, "I am so happy to see Terra standing like a normal child. She must keep practicing on these

new legs so she can sustain herself when she is older. Terra was afraid of the metal legs at first as she didn't know what was happening. But now she can see the results she just wants to keep trying to walk on them."

When the family last saw Terra, she was dragging her body through the dusty earth to get around. Boniface is looking forward to seeing their faces when he brings Terra home. "I am very excited to take her back to our village. We thought her situation could never be improved. But now she will walk into our village just like any other person and be able to go to school and get a good education."



Theresia*

Adorned in her brightly coloured kanga, Theresia quietly moves amongst the twenty other women on the VVF (Vesico-Vaginal Fistula) ward at CCBRT's disability hospital. She encourages the other patients, young and old, with a ready smile, lifting the spirits of those that surround her. Yet a few months ago her own baby girl died during childbirth.

Already a mother of four children, Theresia, a farmer from Mpwapwa village near Dodoma went into labour in June 2008. After two days of labour at home and with no midwife or medical staff available to help, her condition worsened. The family borrowed a vehicle and set off on the four hour journey to hospital. But it was too late. The dead child had to be delivered by vacuum extraction.

After the prolonged labour, Theresia developed fistula and was leaking both urine and faeces. The continual pressure of the baby caused a hole to appear between the vagina and the bladder (vesico-vaginal fistula - VVF) and the rectum and the vagina (RVF). She explains, "It was a terrible time. For months I just stayed in my house. I could not work the land or help provide for my family. All the financial burden

was on my husband. We live on 1,000 Tanzanian shillings (about half a euro) a day growing onions, maize and ground nuts. So when I could not help with the crops, there was even less money to go round." But Theresia's condition did not just have implications financially; socially it also put a strain on the family. "People shunned me because they said the smell was so bad. I was not invited to anyone's home. The worst part was when my own brothers said that they did not want to see me."

A friend told her about CCBRT. "I was happy to hear there was a place that could help me even though I have very little money. But I was scared of the long journey by public bus. The journey was very difficult for me - it was hard to change my pads."

Four weeks after her RVF and VVF surgery, Theresia is dry for the first time in months and ready to make the journey back home. "I will tell everybody about CCBRT, I will tell them about the work that they do. I have seen children with bad legs cured as well as people like me and I will tell people that there is a place they can be helped even if they do not have money."



Nusura*

Brought up in a loving family, Nusura is a happy and confident child. The nine year old says that when she was small she did not notice that she was any different to anyone else. She explains, “My parents made me feel loved and were always positive about my white skin. But as I got older, I noticed people teasing me because I am different. Sometimes it makes me sad, but I just stay quiet and ignore these people. They don’t know anything.” Born with albinism, Nusura needs to protect her skin and eyes from the hot African sun. Every day she uses a high factor sun cream, wears long sleeves, a hat and sunglasses when she is outside. But wearing these protective clothes makes her feel different to everyone else so her teachers and parents have to frequently remind her to put them on.

All people with albinism have low vision. They lack pigment in their eyes which leads to poor vision development. They also have nystagmus, a condition which means their pupils move left to

right quickly trying to search for good vision. No surgery is available to improve the problem. Nusura explains that it became very hard to read the words on the school blackboard and she could only see things that were very close.

Following an assessment at CCBRT’s low vision unit, Nusura was given sunglasses, spectacles and a telescope. She now sits in the front row in class and uses the telescope to improve the contrast of the words on the board. “The telescope has really helped me,” she says “but if the teacher writes small letters, my friends, especially my best friend Zainabu, whisper the words on the blackboard to me so I can do my work.” Nusura will have regular check-ups at CCBRT’s low vision unit enabling her to carry on with her school work.

“I shall be a doctor like my grandmother when I grow up”, proclaims Nusura confidently. “I shall work hard at my science and I shall do it.”



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