THE OKWALOS CELEBRATE CHILDREN WITH DISABILITIES

By Ritah Mukasa

Bridget Nabirye Okwalo and her husband, Emmanuel Okwalo, recently opened their home in Sentema village, Wakiso district to a very special celebration. The couple hosted a Christmas party on December 6 for more than 150 children, many of them living with disabilities, together with their mothers. The joyful gathering, filled with gifts, music and laughter, also marked a deeply personal milestone: the 10th birthday of their daughter, Zion Elizabeth Janelle, who lives with severe cerebral palsy.

The couple also donated a well-equipped facility (St Johns Sentema children's shelter); a safe space for 25 children with disabilities. It is located at Sentema Church of Uganda Primary School.

Nabirye, 35, is a human resources manager at Humanity & Inclusion (H&I), an international organisation. For the past 10 years, her life has been a roller coaster, with unpredictable highs and traumatic lows, given that her second child, Janelle, lives with severe Cerebral Palsy (CP).

Dr Fred Nalugodha from Uganda Virus Research Institute (UVRI) describes CP as a group of permanent neurological disorders that affect movement, posture and co-ordination. It is caused by damage in the brain before, during or shortly after birth.

Janelle's brain, too, was severely damaged during birth. And as such, she can't do anything by herself; be it feeding, bathing or easing herself. Her neck, legs and hands are floppy, yet she also has low vision. The frequent seizures complicate her condition more. Making it tougher for her parents.

However, in that dark cloud, Nabirye and her husband, Okwalo call Janelle their silver lining.

"Janelle is a special gift to us. She has taught us to love selflessly," Nabirye says.

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THE PREGNANCY THAT CHANGED EVERYTHING

Nabirye was born into a middle-income family. Her father, Dunstan Balaba is permanent Secretary at the Directorate of Ethics and Integrity and her mother, Mebra Mutesi, is headteacher at Kikuube Primary School in Buikwe district.

After school, Nabirye worked hard and envisioned living a comfortable life with a healthy family of her own. But fate had other plans.

When her first born was two years old, she conceived again. It was a peaceful pregnancy; no morning sickness, nausea or funny cravings. In fact, she remembers enjoying that pregnancy more than the first one. By that time, she had resigned from a job as receptionist to look after her son.

Meanwhile, the pregnancy progressed well, but things changed during labour. It became prolonged. Doctors were certain Nabirye would push. She had no complications. Indeed, she tried in vain and the baby was getting tired.

At 11:00pm on December 5, 2015, Nabirye was wheeled to the theatre.

Looking back, she says: "At that time, the damage had already been done."

In the process of pushing and failing, the baby's brain was severely damaged as the operation went on well and the baby came out healthy, weighing 3.8kg.

Nabirye recalls: "While in the recovery room at around 4:00am, I started having severe contractions again."

She was tempted to think, maybe she had twins and the surgeon missed the second baby. The pain intensified. She cried and wailed in vain. Later, she started to bleed and the pain stopped.

"It was a lot of blood and that was a bad sign," Nabirye says.

The doctor examined her, but couldn't point to the cause of the postpartum haemorrhage. Injections and transfusion did not help. Nabirye was rushed back to the theatre, where it was revealed that her uterus had ruptured so badly that it could barely hold any more babies. She was just 25 years old.

Nabirye's life was saved, but her woes were far from over.

Back in the ward, she says, she was devastated to learn that her baby had been taken to Intensive care and induced into a coma to stop the many seizures. She stayed there for a week.

Nabirye, too, couldn't sit or walk. She was told her internal organs had been affected. Her pressure kept shooting up. And for a whole week she did not see or breastfeed her baby. It was distressing. Good enough, her mother, husband and in-laws were by her side.

Mother and baby were discharged

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Nabirye with her daughter Janelle

'PARENTS OF CHILDREN WITH DISABILITIES NEED SUPPORT'

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after three weeks. However, the months that followed were difficult.

First, Nabirye realised that her baby's hands would be in a fist all the time. She would also nibble at her nipple, making breastfeeding painful.

The paediatrician assured Nabirye that the baby would outgrow it. But it worsened. One day, while returning from church, Janelle convulsed. She was three months old. Her eyes rolled up and she frothed at the mouth. Nabirye was terrified. Her husband was at work.

"My dad told me to rush the baby to CORSU hospital," she recalls.

While there, Nabirye says, after thorough assessments, she was told, 'your child has cerebral palsy. She will not do all the things other children do'.

"CORSU opened my eyes. Janelle used to shake a lot. I did not know those were seizures. I was devastated, to say the least," she says.

A lot went through Nabirye's mind. She remembered the doctor's words that she couldn't have more children.

"It didn't bother me at first because, after all, I had two children, a boy and a girl," she says. But now, reality hit that her baby would never be able to sit, walk or do anything by herself. Her heart sank.

"We live in a society that defines a woman by the number of children she is able to produce," Nabirye says.

However, she thanks her husband, in-laws and family for supporting her through thick and thin.

From then, the couple started visiting different hospitals and specialists. They desperately wanted their child to get better, but nothing seemed to work. The convulsions intensified.

Their breaking point was when they visited a specialist at one of the mission hospitals in Kampala. They waited for hours, and when they finally saw him, he looked at the baby and said: "I have worked for over 20 years and I can tell you, your child will never see. She is blind. Even if she sees things, her brain can't interpret them."

Nabirye's husband burst into tears. Janelle was four months old then.

Amidst that brokenness, one day while at Mulago hospital, Nabirye met an elderly lady who had a child with cerebral palsy.

She told her: "My daughter, stop moving from hospital to hospital. You will not change anything, only waste your money. Just look after your child."

Nabirye lost hope, but she continued with the hospital visits anyway.

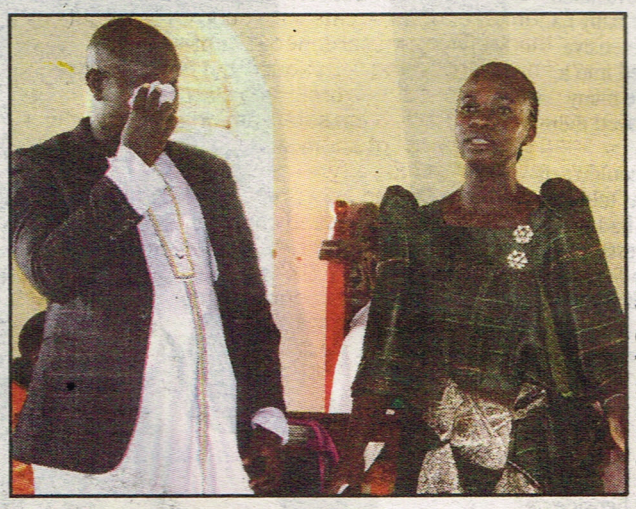
She thanks Gertrude Rose Gamwera, her former boss at Uganda Local Government Association (ULGA), who allowed her to take off time to care for her child.

"I am also lucky to have a mother-in-law who tells her son; that's your wife, and that's your child. Take care of them," Nabirye says.

Meanwhile, by the time Janelle made one year, the couple was still confused and traumatised. They asked God questions on a daily basis. "Why us? Why did you choose to punish us this way after serving you for years?" Nabirye grew up serving in church. In fact, she slipped into depression and stopped going to church. The couple did not even celebrate Janelle's birthdays. These special days did not make much sense then because the seizures continued to worsen, necessitating stronger medication. Some drugs had to be procured abroad, making her treatment expensive.

The Okwalos threw a party for children with disabilities

Inside the shelter which the Okwalos donated for children with disabilities



Nabirye with Okwalo during the thanksgiving service at St Johns Sentema Church of Uganda

HER TURNING POINT

Nabirye remembers a time while at ULGA, she would sit in her office till late without caring how her baby was. She hated going back home.

"I was depressed," she says.

Then one day, she watched a movie that changed her life. It was about a mother who had an autistic child and her husband abandoned her. But her tenacity impressed Nabirye so much that she was determined to emulate her.

This marked the beginning of her healing journey.

In 2017, she made a drastic decision that shocked her family. Nabirye resigned from a job where she was on a three-year contract to her current job, where she was at first given a three-month contract. Little did they know that it was a blessing in disguise because at H&I, part of the work they do is to support refugees with disabilities.

WHAT OTHERS SAY

Rebecca Nankanja, headteacher, Sentema C/U Primary School
The Okwalos are good people. They recently donated a shelter for these children. It is at my school. We welcome all children with disabilities such that their mothers can go and work.

Dunstan Balaba, Nabirye's dad
I thank my daughter and her husband for taking care of Janelle for the last 10 years. Its not easy. But I also urge parents not to hide those kids, but take them to school. Government has put in place systems to support them.

Christine Kirungi, executive diector, Umbrella Cerebral palsy Network Association
I live with cerebral palsy and I am what I am because of my mother. She is my hero. Parents have to sacrifice to ensure their children get the right care on time. It makes a huge impact on how the kid turns out.

"I have learnt a lot about disabilities. I think it was God's plan to teach me how to care for Janelle and other children," she says.

In 2019, Nabirye registered the Janelle CP Foundation, in partnership with her mother and uncle, Dr Fred Nalugodha. They currently support 30 mothers of children living with cerebral palsy in Jinja, Mayuge and Kamuli districts.

WE NEED KINDNESS

"Parents of special needs children go through a lot. First of all, when you have a child with a disability," Nabirye says, "you lose your social life. Friends and family forsake you. Then life becomes extra stressful for us. This child is not the only challenge we have. We experience all the stress other people experience at work and in the family and we add on the child," she says.

Nabirye says having a support system is very important; and that parents need stable incomes because care for special needs children is costly.

"Then you get drained physically and emotionally. Your child needs you, but you're depressed. Society abandons you and you don't know where to start," she says.

Nabirye adds: "It's heavy, and no one can understand, not even your own mother. Even if they are supporting you, they are not feeling that pain. We also suffer the loss of the child that we could have had. Every time you meet a child who is your daughter's age, you think of how she should have been."