EXFAN
Exceptional Family Network

EXCEPTIONAL FAMILY NETWORK | BUYANJA

"HELP US TO HELP THEM"

TEL: +256-702-408845, +256-772-408845
Website: www.exfanug.org | **Webmail**: info@exfanug.org

Ref: .....

THE STORY OF STELLA NANTONGO

In 1979, Uganda and Tanzania were experiencing a war which was to take down President Iddi Amin Daada. During that time I and my pregnant wife lived in a 2 roomed house at Namasuba which is about 4Km from Kampala Rd. Out of the blue the Rocket Paired Grenade hit the house and we lost consciousness for about an hour. I came back to my senses and I summoned my wife, ina thought that she might have got hit by fragments and might be dead, who later replied that "I'm fine, but I cannot feel our child playing, what if she's has died!"This took 21 days when the pregnancy had ceased to make movements, and we came to think that my wife had experienced a still birth.

To save life, We ran away from Namasuba to a nearby village called Ndejje, a very occupied place and we nearly failed to get a house, eventually a good Samaritan who had an animal shelter for his goats agreed to rent us for 3 month thinking that the war was still happening in Namasuba. In a week time seeing Tanzanian soldiers, we decided to return back to Namasuba, and on arrival we realized that the front wall had been damaged and need repair.

At mid-night my wife started experiencing labor pains and she insisted that she could withstand the pain, at exactly 3am in the morning the pains became worse and I ran for a helping hand, a nearby friend denied me his car in fear of being taken forcefully by hash and cruel soldiers. In search for help neighbors joined me to look for a vehicle to take my wife to the hospital. Eventually on arrival to pick her up, she had already given birth to a baby girl named Stella Nantongo. On her birth, legs came out first and never even cried like any other normal kids, her vitals were very weak and down. On the way to rush her to Nsambya hospital, we met about 5 road blocks, and on arrival we were told that Stella is to be put into the incubator.

In a month time, Stella was out of the incubator and we became very happy to have Stella home, but after 6 month we noticed and experienced abnormal conditions and behaviors about our daughter, in the way that "Her eyes could look in opposite directions and then get back to normal at the same time". We got scared and startled, friends, families and neighbors gave us differing advice like to try visiting the Kiganda shrines for Rituals, looking for pastors and among others. We tried all of them and still in vain, by that time my wife also visited a famous American pastor called Usborne, still there was no change.

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As we visited Mulago Hospital we came across a medical doctor who advised us to visit him on an appointed day and narrate to him how Stella was born. We did follow his instructions, Him listening to our story he explained that "She's not Sick, but Disabled. And being disabled cannot be cured but ways can be figured out of how to build a personality for the disabled person."

By the school going age (4-5), it was high time for Stella to start studying, but her main challenge was about speech and we began a search for a School to educate our child, we came across a school at Kireka which was the only one available in Uganda, and by our surprise all the children we found were in a severe condition compared to our Stella, and since we weren't conscious about mental retardation nor developmental disabilities that time, Friends advised as that we can only get good schools in Nairobi and Tanzania, we bordered to Nairobi were we met a school called Jacaranda Special School which had no boarding section, but only day students allowed, in puzzlement we decided to border a bus to take us back to Uganda.

On our way to the bus station along Kenyatta Avenue, we came across gentle man called Patrick Wanyama a friend to date, who greeted Stella in Kiswahili and smiled as if she knew the man, and we were forced to stand. We asked the man that how have you been able identify our daughter to even give you a smile, by the conversation he replied that "I work among such children and I know two boarding schools in Kenya one in Mombasa and the other in Nyeri province of Mt Kenya, and that near Mt Kenya, there is my cousin"

Happy as we were, we asked him to direct us, to Nyeri province which was 100Km away, Later we bordered a bus which drove us up to Karatina Special School. Our child got admitted but on condition that our child being a foreigner was the only one to pay tuition and we were to attend each and every meeting besides us coming from afar and failure to do so would result into expulsion of our child, which we obeyed for 4 years.

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Uganda was not in good terms with Kenya during that time and I continuously met with Patrick, he also worked with a certain law firm along Kenyatta Avenue, into the restaurant he challenged me that "Is your daughter giving you so much burden? And I know that you are a teacher by profession, why don't you return to Uganda and start up a school for disabled children",

Following his words I went back to Uganda and i made a radio announcement, I got surprised as people turned up in multitudes at Bat Valley Primary School; Indians and honorable like Moses Ali, second prime minister, they also came with their children thinking that I was a medical doctor, I came up with the suggestion of starting up an association/organization which will be organized to foster the disabled children,

On 7th July,1991 we founded our Association/Organization called Concern for the Mentally Handicapped Association but through various transformations we established Exceptional Family Network (EXFAN).

Through Mr. Wanyama Patrick a technical director of Special Olympics Movement Kenya, gave me an address to the founder Mrs. Eunice Kennedy Schneider, I wrote to her, she replied "All is noted but we will give you tactics of fishing"

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In 1992,in partnership with Special Olympics Movement basically on sports, Stella travelled 3 times, to America, North Carolina, and Dublin in 2003 to participate into games. Exceptional Family Network (EXFAN) lagged behind, I realized this in 2009, and I stepped down as national director for Special Olympics to concentrate on EXFAN.[WITH AN OBJECTIVE]

BUT NOT LIMITED TO Programs like Green Acres Centre with projects like Green Acres Primary School Buyanja located in Masaka district and many others. Now we need EXFAN to support children holistically.

The absence of an organization in Uganda that suits the demands of the vulnerable and mentally handicapped contributes to high levels of knowledge gap among them. Like Stella Nantogo who inspired me to start exceptional Family Network.

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