



3 STRONG WOMEN

TANZANIA OCTOBER 2021

Dear Child-Help friends,

2021 was marked by more than just COVID-19. Another 1 million families worldwide were affected by spina bifida and hydrocephalus. An estimated 80% of them living in the Global South where the majority is deprived of any help. In Uganda, one of our focus countries, our partners perform 2000 surgical procedures every year, which is one third of the actual need. That in itself is already a great success, especially in times of COVID-19 when access to care is even more difficult than before.

As I write this introduction, an inconceivable war is raging in Ukraine that rightly demands all attention. Since Child-Help also provides emergency aid we were able to switch quickly and to send medical equipment and support qualified personnel in the war zone. Our main focus however remains spina bifida and hydrocephalus in the Global South. The continued support of thousands of donors helps Child-Help make a difference for its target group every day.

My latest travelogue takes you into the story of three strong women. Gertrude is one of them.

Her smile and her view of the future are the greatest reward for our efforts. Because she shows what is possible. She has spina bifida herself and shares her experiences with fellow sufferers in our House of Hope in Mwanza.

Since June, we have our own country representatives for Uganda and Kenya. This strengthens our work in the field and gives our partners in the South more and more responsibility.

Houses of Hope provide a haven for children with spina bifida and/or hydrocephalus and their parents who often find themselves in hopeless situations. They provide a home before and after surgery and a place where parents can learn from each other. Parents take an active interest. They work in the garden and cook meals together. Child-Help already counted several Houses of Hope and in 2021 we started new ones in Guatemala, Zanzibar and Uganda.

Child-Help has taken an important step by making Oxybutynin available locally. It is a drug that relaxes the bladder and is crucial for preventing kidney damage and achieving social continence. Oxybutynin can now be legally imported into Uganda, packed there and transported to 6 other African countries. Currently, several hundreds of patients are benefiting from this. That could well increase to thousands in the future.

Besides Gertrude you can also meet Edna and Mwajuma.

Wishing you lots of reading pleasure!

Pierre Mertens
President Child-Help International

EDNA

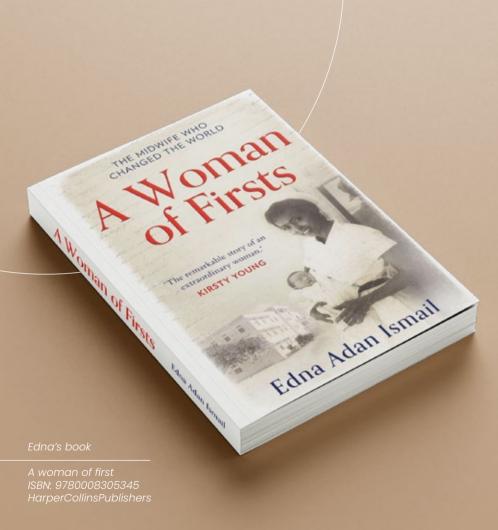
I lied to **Edna Adan Ismail** when, during a Zoom meeting with her second cousin Nimo and the young, veiled doctor Srushi, I said that I had read her autobiography.

Edna shyly turned her head away and hid behind her palm like a timid 8-year-old girl. Edna is a young sprightly eighty four year old. In 2002 **she set up the maternity and children's hospital** in Hargeisa, Somaliland, that we intend to cooperate with.

Dr Dick Bransford, who is also approaching his eighties, has been asking me for years to travel to Hargeisa with him. In the late 1990s, he worked as a general surgeon in Kenya and contacted me for shunts. This resulted in a collaboration that lasted for years and provided thousands of Kenyan children with the necessary surgery and follow-up. When he had to retire as a missionary doctor, he flew to Hargeisa every six weeks to operate on children with spina bifida and hydrocephalus. This is how he came to train Dr. Srushi and provide her with our shunts for many years.

In Edna's hospital, he met Nimo, who was on a visit there. A young lawyer who was given asylum in Belgium with her Somali family when she was 10 years old. Dick convinced Nimo, a Somali Belgian, to contact me, his other Belgian acquaintance, with a view to working together.





A veiled Nimo contacted me from Edna's hospital via Zoom and set the ball rolling. In Belgium I met up with her again, this time fashionably dressed, without a veil hiding her beautiful head of curly hair. Nimo, a child of two cultures, now wants to return to Africa.

Edna's tome had been lying on my shelf until I picked it up again last week. I started reading it and decided to take it with me on this trip.

With Edna I am on my way to Tanzania to visit our projects after almost two years of COVID-19. The pandemic is having a severe impact on our target group.

Hospitals have been taken over by patients affected by the virus and everyone else has to wait. During a Zoom call yesterday with Dr Ron Baticulon, a neurosurgeon based in Manila (the Philippines), he stated that among all the other problems disadvantaged parents have in getting to a hospital in time, COVID-19 is now the biggest obstacle. The large government hospital in Manila has been completely taken over by the pandemic.

Travel from the hundreds of islands is virtually impossible. The doors of the main surgical centres remain closed to our children.

The first chapters of the book tell the story of Edna, who as a little girl 80 years ago, had to fight gender inequality in her culture. It sounds like a Taliban narrative in which girls are not allowed to play outside, have no right to education and are prepared for a life of servitude to their husbands and children. This injustice reaches its painful nadir in a gruesome unannounced circumcision at the age of eight. The circumcision of young girls continues silently like a smouldering fire fuelled by the collective silence of women who were once themselves victims of the same trauma. It took Edna almost 80 years to write it down. Long before that, she had openly revealed herself as a victim of, and activist against, this injustice.

Making these silent victims a subject of discussion is fundamental, as are racism, homophobia, MeToo, Black Lives Matter, incest and, please bear with me, inaccessible health care for children with spina bifida and hydrocephalus in most developing countries.

Edna's testimony truly humbles me, a white-haired old man on a mission to Africa, who has never suffered hunger, been through a war or had to flee for his life. In fact, I would like to hide behind my palm, just like an eight year old little girl.

Because as a result of all the super-efficient zooming I have lost touch with what really matters: mothers with a severely disabled child, often abandoned by their husband, looking for help in an inaccessible health care system.

Despite the fact that they offer many benefits, video conferences often overlook the complexity of things. Meetings don't require long, polluting flights such as this one. You can discuss and question things face to face, i.e. screen to screen. Being mega efficient, I proceeded from one meeting to another over the past year without the mental adjustment it takes to actually visit somewhere and make the return journey. It is not unlike the difference between sending a quick e-mail or taking the time to post a handwritten letter with an attractive stamp to a friend. This journey feels like a kind of rehabilitation from zooming.

I visited **our new office in Dar es Salaam** for the first time. It is located in a now abandoned shopping centre that went bankrupt due to COVID-19. A large communal meeting area is surrounded by offices, two of which we rent. Beautiful images on our windows and doors show at a glance what we are all about: mothers, babies in need and primary prevention. Janet, my Tanzanian colleague, has built up a well-motivated team whose members are not afraid of hard work.



I also see the **brand-new House of Hope in Zanzibar** for the first time. The building, which is painted in warm hopeful colours, now accommodates eight mothers and children. They are all there for a good reason. They are waiting for surgery or are recovering before they can go home. Some originate from other islands such as Pemba and Mafiaö.

Meanwhile, little Edna had the opportunity to attend clandestine classes organised by her father at home for boys from the neighbourhood. Being the daughter of the house, she was tolerated at the back of the room, but she was not allowed to ask questions or give answers. Somaliland was an English colony at the time. Edna admired her father who, as a physician associate with few resources, helped hundreds of people and even performed minor operations to save lives.

What do you do when no doctor is available and a mother and child are in danger of dying because hydrocephalus prevents the baby from descending into the birth canal ready for delivery? You perform a caesarean section, even if you are not a doctor. This is not about pride or self-aggrandisement, but a matter of life and death. At an early age, Edna was allowed to accompany her father to the hospital, where she was gradually given more tasks. She dreamed of one day becoming a real nurse and building a hospital for her father.



MWAJUMA

In the House of Hope, I sit next to **Mwajuma Khamisi**, Fatima's mother. Hydrocephalus had been diagnosed by ultrasound during pregnancy, which is why she gave birth by caesarean section.

It was not a straightforward delivery. She herself was unconscious for three days after the operation and Fatima was injured during the operation. She has a large scar on her head, which made me think that she had already been fitted with a shunt, but that it was not functioning as Fatima is clearly showing signs of acute overpressure. But no, Fatima, now 6 months old, has not yet undergone the operation to which she is entitled.

When Mwajuma recovered from the caesarean section and the wound on Fatima's head had healed, they were sent home and asked to come back in two months, because the baby's skull would have been too soft for an operation. During her first admission, her husband still supported her, but after a while he started to beat and abuse her. The family got together and tried to mediate, but the husband no longer wanted to have anything to do with his wife and Fatima.

Mwajuma gets tears in her eyes and says: "God gave me this baby and I will take care of it." She left her husband



and together with Fatima moved in with her parents, who are now looking after her. After two months, she returned to the hospital hoping for an operation for her sick child. She was referred to the House of Hope because there was a long waiting list. Due to COVID-19 there is a major shortage of oxygen. She has been waiting in the House of Hope for months now and is awaiting the arrival of the Spanish doctor Piquer who established an impressive neurosurgery unit at the hospital. He is set to arrive in a few days' time and will then stay for two months.

The staff at the House of Hope are doing everything they can to help Mwajuma and to keep her spirits up. "We are all waiting impatiently together with you: you have a special child and Fatima is lucky to have such a special caring mother", I comfort her.

A House of Hope is also meant to be a place where you are not alone facing sometimes hopeless situations.

Edna is given the opportunity to study nursing in London by the British occupiers.

When she returns to Somaliland as a midwife, she has to deal with many complex situations with far fewer resources than she had access to in London. For example, the circumcision of girls causes huge complications right through from conception to childbirth.

The lack of resources, waiting lists, failures... Edna's book describes it all in great detail. The difference between the North and the South is immense. Child-Help wants to try to bridge this gap by converting our high-tech, sometimes over-active medicine into preventive care. Fewer and different kinds of interventions, but better for mother and child. Any treatment or examination often has side effects. For example, we lose children every day because surgeons demand an expensive, sometimes unnecessary CT scan before they will act. If parents cannot afford this, they are removed from the surgery list, but the child's head continues to expand and the child becomes blind or dies a slow death. A scan shows a momentary image rather than the actual development. If the head has stabilised and there are no clinical signs of overpressure, surgery must not be performed. This development can be monitored by measuring the head circumference using a simple tape measure, which doesn't cost anything. The absence of a

CT scan should not be a reason to refuse surgery when the child's brain is at risk.

The hospital is unable to find Fatima's dossier and during a Zoom call with Dr Piquer I ask him to see the waiting mother and child as a matter of urgency. I fear that in the meantime the girl on the waiting list has gone blind.

On her return to Hargeisa, her country becomes independent but merges with Somalia, which was under Italian influence. This is clearly against the will of the Somalis. During the Berlin Colonial Conference (1885), Western powers divided Africa into sections, as if it were a cake.

The whole of Africa consequently remains burdened by its colonial and post-colonial past, in which these unnatural fault lines create border conflicts that continue to divert money away from the health sector.

Edna experiences it all. Her husband becomes Prime Minister and is subsequently side-lined by a military coup. He is sent to prison for many years. Having enjoyed unusual wealth, she descends into sheer poverty. At the age of sixty, this strong-willed woman finally manages to build the hospital of her dreams.



RESULTS 2021 Members of Child-Help International Project countries Focus countries Material support

IVOORKUST

78 children followed-up

3 surgeries

90 shunts

GUATEMALA

44 children followed-up

44 new in 2021

PERU

14 children followed-up

10 new in 2021

293 family members trained

37 professionals trained

6 surgeries 225 clinics

335 new in 2021

9 professionals trained

SOEDAN

298 children followed-up

73 family members trained 12 professionals trained

27 surgeries

OEGANDA

3.368 children followed-up

720 new in 2021

690 family members trained 109 professionals trained

1.346 surgeries

71 clinics

1.453 shunts

ETHIOPIË

3 professionals trained

740 shunts

KENIA

4.042 children followed-up

485 new in 2021

198 family members trained 7 professionals trained

68 surgeries

129 clinics

171 shunts

⊚⊘

12.379 children followed-up worldwide

16.409 mothers worldwide received a year's supply of folic acid

30.363 catheters provided worldwide

164 family members trained

13 professionals trained

2 surgeries

4 clinics

DR CONGO

116 children followed-up

42 new in 2021

267 family members trained 5 professionals trained

11 surgeries

25 shunts

ZAMBIA

1.169 children followed-up

96 family members trained

254 surgeries

2 clinics

TANZANIA

2.174 children followed-up

588 new in 2021

823 family members trained

24 professionals trained

461 surgeries

46 clinics

1.055 shunts

MALAWI

778 children followed-up

561 new in 2021

300 family members trained

22 professionals trained

352 surgeries

321 clinics

ZUID-AFRIKA

298 children followed-up

25 new in 2021

42 family members trained

8 professionals trained

1 surgery

Parent Group

Hospital Project

Outreach Project

House of Hope

Continence Management

Planned Hospital Project

Planned House of Hope

5.976 pieces of surgical material provided (shunts, EVD, ...)

GERTRUDE

We fly from Zanzibar to Mwanza, where the newly built **House of Hope** welcomes 18 mothers and children, all with their own story and good reasons.

The building is attractive and welcomes our parents respectfully. It is their home, which they maintain together and where they cook and work in the garden. Everyone is busy at seven o'clock in the morning, and no one stops for breakfast until after eight.

They are invited to use colours to explain their feelings. Green means 'I am happy'. Orange is OK, but I'm struggling with something. Red means 'I'm not doing well'. Gertrude leads the conversation. A lot of green, because sometimes they are heard for the first time, but also orange and red. Orange, because a mother of twins is afraid that her husband will not show up at the hospital tomorrow. Red, because a mother just heard that her father died of diabetes and that her child with spina bifida is to blame.

Gertrude asks me to introduce myself. I hesitate, because Liesje, our daughter, died when she was almost 11. Is that the message I should pass on to these young mothers? However, I have learned that it is important to tell the truth. I talk about Liesje, and my voice falters. Even after all these years, I still can't talk about her without becoming emotional. The tears are also a comfort, because they tell me that she is

still a part of me. I avow that I am one of them, that more than 40 years ago I was not given the information that Liesje could be helped. "I know what you are going through. I am like you."

At 7 o'clock the next morning three mothers leave to go to the Bugando Hospital for treatment. Fortunately, the father of the twins showed up.

In a corner, Gertrude is teaching a mum and her son how to perform colonic irrigation. After dinner, all the mothers sit together and Gertrude provides information about spina bifida and hydrocephalus. I am allowed to attend listing to whispered translations.





Gertrude is doing an excellent job, the mothers ask pertinent but tough questions, also about the cause of their child's disability. Will my child be able to walk, carry water on their head, enter into relationships, study, conceive children, grow old? You cannot provide simple yes or no answers to these questions. You can relate the tales of the many who did just that, but that does not offer a guarantee for their child.

Perhaps Child-Help with reference to Liesje, who did not make it because of an ill-judged medical error, can act as a fair correction of the success stories that I also tell. Of children who became doctors themselves or, like Gertrude, who has spina bifida and became a social worker. We sit down separately and **Gertrude tells her story:**

I was the first born in my family and my parents immediately accepted me as I was. My mother is deeply religious and spiritual. She believes that everything has a meaning. However, her immediate environment reacted with hostility: she was told that I was a disgrace to the family and that I would never achieve anything. People here despise children with disabilities and consider them the cause of much evil, such as diseases that may afflict them. Some even suggested that I should be killed to protect the family and the clan from harm.

But my mother believed in me. She encouraged me to go outside and make contact with my peers. My father preferred to keep me inside, but my mother persevered and later sent me to school. She instructed me on how to catheterise so that by the time I was 6, I could do it all by myself. She taught me to have confidence in myself. For example, I didn't have the confidence to walk without support, but bit by bit I succeeded. I learned to survive, but it was made really difficult by an environment that humiliated and often excluded me. I saw girls leaving and I asked them to wait, but they ran off laughing. Something like that chills you to the bone and it made me feel very insecure and sad.



I have a younger brother and a severely disabled sister. She could not walk or talk. She had constant epileptic seizures and died when she was 16. My mother also had two miscarriages before my sister came along, but despite such misery she did not stop fighting on my behalf.

School fees became a problem because my father had no job. We lived in abject poverty. So that I could study, Mum and I would collect and package nuts to sell to local shops. I bought a second-hand computer and sold songs I downloaded from the internet.

Secondary school was a boarding school. Only my room-mates knew about my incontinence. I also had to tell the carer, because sometimes I had to leave lessons to deal with my catheter. The headmaster supported me to invest in my singing, acting and musical talents.

However, when my father entered into a relationship with another woman we were in dire straits. I had to interrupt my studies and eight years went by



without any form of education. It was the bleakest period in my life. I felt very alone and vulnerable. I became pregnant and the father of my child wanted me to have an abortion. I never saw him again. I named my son Georvin, after a popular radio producer in Arusha. Eventually, an uncle sponsored half of my school fees, which enabled me to go to college. Not to study journalism, which was my dream, but

social work. Otherwise he was not prepared to pay. By selling nuts and music I made up the other half, although this was often problematic.

My uncle then became ill and was no longer able to pay. My teachers looked down on me and humiliated me. Other students didn't like me much either. The headmaster of the school offered to help me financially if I would have sex with him. He abused many girls in the school this way and it was said that he was HIV positive. I thought about my child and refused, but my study dream fell apart. I was not allowed to sit my exams after the penultimate year of my studies because payment of school fees was a condition for sitting exams.

My father fell ill and moved back in with us. And then I met you, Pierre. It was as if you were an angel sent by God. You paid my debts and advanced my school fees until my final exams. I could pay back this loan bit by bit by working for Child-Help. My life changed. Even the teachers at school started to like me and admired my

courage and perseverance. I was even held up as an example to other girls. I regained my self-confidence. When I passed my final exams, Janet called me and I could immediately start working for Child-Help and pay back my loan bit by bit. Child-Help gave me a job in the House of Hope in Mwanza, where I am still working today.

I can now buy clothes for my son and he has a real school bag. He doesn't have to face the same difficulties as I did going to school in rags and torn shoes. Because poverty was more humiliating than my disability.

The amount of money I pay back is small, which means that I can take care of myself as well as my family.

If you ask me if I like my job, I have to say no. I don't like it, but I love it. I don't like the actual work, but I love what I do. I am on an equal footing with the mothers and can really make a difference in their lives and that is the most rewarding aspect of my work.

When I met you in Arusha, you told me that I will definitely find a good man. That gave me courage. I have now met a man, who is a bit younger than me but he is kind and caring. I told him everything about me, including my disability and my son. Having said all that, I'm afraid of being hurt again. He is an animal keeper but has no job. He wants to marry me and even speak to my parents but I am afraid that his family may not approve of me. I would like your blessing before I decide to share my life with him.

I propose a Zoom call, but do not promise that I will give my blessing. Relationships are always problematic and complex, but that is why they are so fascinating. In her case the blessing has to come from within.

Meeting her boyfriend will no doubt involve another Zoom call...

I lend Edna's book to Janet. Inspired by Edna, Mwajuma and Gertrude, three strong women with the same sense of determination, I travel back to Belgium.

They will always remain an inspiration.



COLOPHON

The financial report can be requested via: info@child-help.international

Foreword

Pierre Mertens

Text

Pierre Mertens

Layout

Bert Dombrecht

Photographs

Pierre Mertens Monday Agbonzee Jr.

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Lieven Bauwens

Coordination

Anke Leblicq

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