



CHILD—HELP

**NOTHING ABOUT US
WITHOUT US**

**CHILD-HELP AND DECOLONISATION
ANNUAL REPORT 2022**

De Keyserlei 58–60 bus 19, 2018 Antwerp
WWW.CHILD-HELP.INTERNATIONAL



NOTHING ABOUT US WITHOUT US

2022 will go down in history as the year Russia started an unexpected war in Ukraine. This is because the Ukrainian people chose to be closer to the European Union. Their voice was not listened to, and that is why the Russian invasion draws colonialist parallels to the actions of Leopold II, King of the Belgians, in the Congo at the end of the 1800s.

Child-Help co-founded the Ukrainian spina bifida organisation in 2016, two years after the Russian occupation of Crimea. Through its presence in Ukraine, Child-Help swiftly launched a fundraising campaign and sent emergency aid to the war zone in solidarity with its Ukrainian families with a child with spina bifida.

Child-Help arose from the solidarity between people with spina bifida and hydrocephalus and is active in over 25 countries today. Having faced the same challenges, you understand each other without many words. There is an immediate sense of togetherness and equality. This is universal, regardless of territory or upbringing, and especially when people face the same challenges of languishing under the violence of war.

'Nothing about us without us' became the emancipatory slogan of the global disability movement.

"Nothing about us without us" became the emancipatory slogan of the global disability movement. People with a disability were tired of having others decide for and over them for their so-called good. This led to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), an international human rights treaty from the perspective of people with disabilities.

Child-Help has embraced this convention and translated it into its work worldwide as 'starting at the end of the chain'. With this, Child-Help means starting with the children that matter – where they live and with their parents looking for help for their child. It's about them. Only they can tell you what challenges they face in their lives and what they believe may be a first step towards improvement. Child-Help brings parents together so that they can break through their isolation. You learn so much from your peers.

Nothing about us without us helps us not to think for them but to start with them from their thinking. Colonial history weighs on development cooperation. "Decolonise our mind", says Janet, our Programme Director from Tanzania, later in this annual report.

Based on this equality, Child-Help International welcomed Child-Help Tanzania as a full member in 2022. In this way, we exchange North-South solidarity for international solidarity with programmes across the world. Dr Shabani shares some of his insights in this report as chair of the new Child-Help Tanzania.

The photos are from Rhune Bervoet. She visited some of our projects in Tanzania during her photography studies at KASK in Ghent. We also include a piece of her daily blog here.

We proudly close this difficult year with our results worldwide and are hugely thankful for the efforts of our many loyal donors who made all this possible.

Pierre Mertens
President Child-Help International



DECOLONISING THE MIND

INTERVIEW WITH JANET MANONI ON DECOLONISATION

Child-Help interviewed Mrs Janet Manoni on her view of decolonisation. Throughout her life, Janet, our Director of Programmes in Tanzania, has learned how to put decolonisation into practice. Her choice for Child-Help is no coincidence.

Janet is a YALI graduate. "The Young African Leaders Initiative (YALI) is the United States' signature effort to invest in the next generation of African leaders. The Mandela Washington Fellowship is YALI's flagship programme, bringing future African civic, business and community leaders for academic coursework, leadership training and networking at US colleges and universities. Annually 1000 African young leaders are selected to study in the US and are expected to return home to put the lessons learned into practice. They remain connected via the YALI Network across 49 countries in Africa and are able to access resources throughout."

My aim is to spread awareness about the things we usually shut our ears and eyes to.
- Rhune

The **Mandela Washington Fellowship** is YALI's flagship programme.

Child-Help: "How are people selected for this YALI programme?"

Janet: "In Tanzania, out of 4000 candidates, only 42 have been selected. Graduates who have been to the US motivate and identify new candidates for the next YALI programme. They know exactly what the programme entails and are well placed to encourage the new 'leaders' to join it. So, the selection is done by 'Yalies' of the African country."

Child-Help: “Janet, how did you start engaging yourself with other people?”

Janet: “I lost 3 family members in 3 years: my father, mother and sister. That made me think about what I really wanted to leave behind. I started taking care of people with cancer. I saw a huge and widening gap between a number of doctors and patients and their families. Some doctors needed to improve their communication with patients. Bad communication frustrated me, so I started working with children with cancer. I honestly was hoping to be healed from my great loss, but it was difficult because some children with cancer do not make it – it is so hard to remain hopeful. I came across children with hydrocephalus and asked the doctors what that was. The challenges children with hydrocephalus face are very similar to those with cancer. I therefore started focusing on care for children with spina bifida and hydrocephalus. I was fundraising locally for the work I did, and that is when I met Child-Help.”

Child-Help: “When you, Janet, began the fight, it was a fight with your own system, your own doctors. You wanted to improve the local system with local resources?”

Janet: “Yes, often the third party can hinder your own mission, as everybody is looking for their own opportunities to make progress. Financial independence will give me the power to decide.”

Child-Help: “What does decolonisation mean for you?”

Janet: “The thinking about decolonisation started in the ‘60s. For me, it started with the book ‘Decolonising the Mind: The Politics of Language in African Literature’ by the Kenyan novelist and post-colonial theorist Ngũgĩ wa Thiong’o. The book is a collection of essays about language and its constructive role in national culture, history and identity. It advocates for linguistic decolonisation and is one of Ngũgĩ’s best-known and most-cited non-fiction publications. During my lifetime, I have come to learn how to put decolonisation into practice.”

Child-Help: “How should external funding be organised in a decolonial way?”

Janet: “International support and local support have to be in balance. Mutual understanding is crucial. I have this, and you have this; how can we combine this and work together? This I found within Child-Help. One plus one is three. Child-Help does not support African doctors to study abroad and then return to Africa; Child-Help supports South-South exchange wherever possible, giving training on the spot, within the resources of the hospital. Our professionals try to translate international knowledge into the best care possible, in local circumstances and with local means. Sometimes this means doing less but better. They do not expect the same means and advanced technologies they have seen abroad; they put their knowledge into practice using African resources.”

During my lifetime, I have come to learn how to put **decolonisation** into practice.

*Children know a lot about life around here and that is largely due to the experience they gain here.
- Rhune*



Child-Help: “All done by local people?”

Janet: “Within Child-Help, we believe in the South-South exchange of knowledge, not in doctors flying in and leaving again. We work with grassroots organisations and initiatives, caregivers and parents that are on the ground by empowering them – not supplying fish, but teaching them how to fish and building on the existing knowledge of fishing. We have built up people like the YALI programme does, and we build on already existing local organisations. Parents can bring about changes in the system by informing their politicians appropriately. We begin at the end of the chain. Where the families and the children are, is where you find Child-Help.”

Child-Help: “So, is Child-Help doing better on decolonisation compared to other NGOs?”

Janet: “To be honest, Child-Help is way ahead on the decolonisation process. This has come about organically from the humanistic understanding and values which are guided by our bottom-up approach and horizontal decision-making process. Of course, this is a work in progress which keeps us alert and helps us check what we are doing at all times, as it clears the mind.”

Child-Help: “What is decolonising the mind?”

Janet: “We are children of decolonisation. My mother was born in 1940, under colonisation. Being a product of colonial times, you can imagine the kind of knowledge she installed in my mind. The effects are severe. Every day you have to make a choice: Do I want to be a victim, or do I want to take the future into my own hands?”

Child-Help: “How about the need for governments to take care of children with spina bifida and hydrocephalus? The need for a well-functioning social security system in each country so that everybody can be treated and nobody is left untreated because of poverty?”

Janet: “The people can force their government to have a well-functioning social security system. I believe in it 150%.”

I hope that people will get to hear the voices of these mothers. – Rhune

To be honest, **Child-Help** is way ahead on the **decolonisation process.**



In Africa,
education is
100% a product of
colonisation.



From the audience: "How about education?"

Janet: "Education is a huge component of decolonisation. Education is supposed to be the foundation for life. In Africa, education is 100% a product of colonisation. In traditional cultures, families had careers, there was a division of labour, and when you were born into a family with expertise in a certain field (e.g. carpenters, butchers, farmers, etc.), you made a career in that field. That was your future. The colonials came and did not understand the traditional education system. Now, an exam of one day determines your future, not a lifelong achievement. Decolonisation is going back to the traditional culture and thinks what the place of these traditions can be in the future of a country.

A foreign power can never completely grasp the culture of a people, what their values are, how people's minds work or how the society is traditionally organised. A country needs to determine its own future. The people need to fight for their rights and the rights of their children. They need to force changes and reforms themselves."

*By offering others opportunities,
you offer yourself the chance to develop
your humanity. - Rhune*





CHILD-HELP TANZANIA: IT'S ABOUT US.

INTERVIEW WITH DR SHABANI

We meet Dr Shabani in between surgeries. He has kindly made time for us and greets us with a broad smile.

Dr Shabani is a Consultant Neurosurgeon and Chief of Paediatric Neurosurgery at the Muhimbili Orthopaedic Institute (MOI) in Dar Es Salaam and President of Child-Help Tanzania.

Dr Shabani: "Many children come from far away. We are a reference hospital for the whole country. Distances are big in Tanzania, and treatment centres for hydrocephalus are few. Because we have treated hydrocephalus, local doctors often refer children to us unnecessarily for common illnesses such as malaria or flu. But those cases requiring vaccinations or treatment for flu should be handled locally.

Children with hydrocephalus need to be followed up neurosurgically. If a child does not show clinical signs of overpressure and the head has stopped growing, you should not operate.

When the child is older and the skull has grown together, hydrocephalus can become an urgency. Then action must be taken quickly. However, I would never do a preventive shunt when no progressive hydrocephalus exists.

Some protocols state that all hydrocephalus patients should have a CT or MRI scan. In many countries this is free for the patient. But not here. A CT scan here costs USD 200 and an MRI costs USD 250. That's roughly equivalent to an officer's salary! With babies, you can already see a lot with ultrasound. Here at MOI, children receive an ultrasound and, only if necessary, a CT scan.

In the late 1990s Child-Help International, then part of the International Federation for Spina Bifida and Hydrocephalus (IF), started a collaboration with a new disability hospital organised by another international NGO in Tanzania. Your chairman Pierre Mertens was then still chair of IF. Everyone was happy because Child-Help had introduced the Indian Chhabra shunt and donated it to parents for free. The hospital received training and resources from Child-Help so they could properly follow up and offer physiotherapy with a holistic approach to each child. But the hospital withdrew the services in 2005 – their new management considered them too expensive.

I tell her it is important that she lets go of her emotions and that her feelings are valuable. – Rhune

Fortunately, Child-Help had brought the parents together from the start, and ASBAHT, the Tanzanian association for spina bifida and hydrocephalus, was born. Organised and empowered to lobby, they went to the press and the government, which gave MOI the opportunity to take over the SBH activities. When Pierre visited me in 2006, I showed him what we had been doing since the hospital stopped its services. Child-Help was then very involved with Dr Benjamin Warf in Mbale (Uganda), where the endoscopic third ventriculostomy and choroid plexus cauterisation procedure (ETV/CPC) was further developed.

Child-Help had given Dr Warf his first endoscopic installation, which was also possible for MOI. That was my first contact with Pierre. I received an ETV machine and he introduced me to Dr Warf. Child-Help has meant a lot to the treatment of these children here.

ETV/CPC makes a big difference to the future of these children. Professor Benjamin Warf of Harvard Medical School and Boston Children's Hospital, who started combining ETV with CPC, did a lot of research in Uganda. It was Child-Help who asked him to work with a flexible scope. In addition to the ETV, choroid plexus cauterisation (CPC) can be performed safely with a flexible scope.

We also intervene in the production of cerebrospinal fluid with much better results. Dr Warf followed a series of patients for 5 years and has published more than 6 papers on this, and the publications showed very clearly that when we, surgeons, do a combined procedure, ETV and CPC, in children, it benefits every patient.

At a presentation I gave in Nairobi, Kenya, on the ETV results for 250 children under 2 years old whom we had operated on, I met Professor Graham Fieggen, a well-known professor of neurosurgery for children at the University of Cape Town, South Africa. He really liked the work we did. Professor Fieggen promised me that he would encourage one of my candidates to go there to continue the work and publish our article. This is pioneering work.

Later in 2012, Child-Help introduced me to Ms Janneke Jorgensen, the World Bank attaché in Tanzania overseeing nutrition programmes. I presented our initial hydrocephalus spina bifida research findings at the Food Fortification Initiative (FFI) meeting in Dar es Salaam. From there we won in convincing the government to adopt mandatory folic acid fortification of maize and wheat flour from the large-scale millers under World Bank sponsorship.

Where they can't find the strength in their unbearable situations they do find strength in each other. - Rhune



Organised and empowered to lobby, they went to the press and the government.

Do you know what my drive is in this work? Obviously, as a doctor, I want to provide the best care. But it's the children that make me do it. Children are not like adults; they never complain."

Child-Help International asked me to start Child-Help Tanzania (CHT) in 2019. CHT is now a full member of CHI. CHT represents CHI here in Tanzania and can develop its own programmes and funding. There's much work to do! The newly appointed director maps out all the initiatives related to spina bifida and hydrocephalus and exposes the shortcomings, not only medical but also education, clean intermittent catheterisation (CIC), rehabilitation, wheelchair provision, shunt provision, equipment maintenance, etc. As the collaboration is now, it is 100% CHI in CHT, under the name CHT. That's how it should be. They are our Tanzanian children, after all. **It's about us.**"



Do you know what **my drive** is in this work?

This room is quiet and breathes grief. I'm not hearing any laughter or even the sound of people talking. - Rhune



They are our Tanzanian children, after all. **It's about us.**

RESULTS 2022

Members of Child-Help International

Project countries

Material support

- Parent Group
- Hospital project
- Outreach project
- House of Hope
- Continance Mgmt

UKRAINE

262 children followed-up
72 new in 2022
111 surgeries

21.125 children followed-up worldwide

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

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

33.254 catheters provided worldwide

GUATEMALA

156 children followed-up
50 new in 2022
272 family members trained
36 professionals trained
35 surgeries
86 clinics

PERU

379 children followed-up
8 new in 2022
79 family members trained
30 professionals trained
12 surgeries
4 clinics

UGANDA

5.417 children followed-up
651 new in 2022
1.143 family members trained
90 professionals trained
1.922 surgeries
69 clinics
263 shunts

IVORY COAST

8 children followed-up
31 shunts

DR CONGO

440 children followed-up
110 new in 2022
60 family members trained
18 professionals trained
47 surgeries
56 shunts

ZAMBIA

2.514 children followed-up
220 new in 2022
260 family members trained
21 professionals trained
376 surgeries

SUDAN

110 children followed-up
38 family members trained

ETHIOPIA

74 children followed-up
6 professionals trained
494 shunts

KENYA

5.750 children followed-up
471 new in 2022
983 family members trained
37 professionals trained
259 surgeries
105 clinics

TANZANIA

2.149 children followed-up
446 new in 2022
904 family members trained
22 professionals trained
841 surgeries
337 clinics
1.788 shunts

MALAWI

2.705 children followed-up
410 new in 2022
363 family members trained
60 professionals trained
396 surgeries
277 clinics
212 shunts

SOUTH-AFRICA

1.253 children followed-up
23 new in 2022
16 family members trained
3 professionals trained
31 surgeries



These mothers are so strong,
they literally dance through their despair
and together we do the same through the language barrier.
I've never seen such optimism in such devastating situations.
Still, the helplessness is inevitable.

THE WOMAN YOU CAN SEE IN THIS PICTURE IS LUCY.
She is the caretaker at the House of Hope.

Each day from the room I am sleeping in, the first thing I hear
is the sound of Lucy working in the early morning hours
and continuing until the very late hours.
Everyday of her life is in service for others,
I barely see her doing anything for herself.
Yet, even so I never hear her complaining.

Every day, she goes to the market for her children,
as she calls everyone coming here.

House of Hope gives a voice to these women.
Here, they feel understood and they find strength in each other.

- Rhune Bervoet

COLOPHON

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

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*Inclusive school in Dar es Salaam.
Here the children are accepted and learn to function with themselves,
the people around them and their disability. - Rhune*





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