



CHILD—HELP

HOPE

ANNUAL REPORT 2020

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Pierre Mertens and Kyla in Kenya.

ANNUAL REPORT 2020

Because of Covid-19 we won't bring you a travelogue in this annual report, but we will give you reflections of Pierre Mertens on the subject of **hope** in often hopeless circumstances.

Child-Help has a target audience which grows annually with approximately one million babies, born with spina bifida and/or hydrocephalus. Child-Help doesn't receive structural subsidies and works in a world where this health problem hardly receives any attention. The vast majority of these children live in the Global South where access to care is very limited. You would raise the subject of Hope for less. Besides this Covid-19 touched our families even harder because of loss of income, discontinuation of public transport and the lack of hospital beds. It is so bad that we even had to deliver food parcels to keep families alive. Hopeless situations!

Child-Help is aware that only action brings hope and that is why it is so desperately needed.

For that reason, Child-Help focuses on three themes: primary prevention, knowledge development and awareness raising.


Prevention: For spina bifida it is folic acid. We know how we can get folic acid in the blood of young women in a country at the right level. This is possible by handing out supplements to groups at risk and by food fortification for the whole population. Prevention also means preventing secondary disabilities by providing the right treatment as well as timely treatment.

Knowledge development: Child-Help wants to become the knowledge center for all aspects of life with spina bifida and hydrocephaly in the Global South. From preconception to pregnancy, timely treatment, human rights, education, schooling, sexuality, employment to, when needed, palliative care and mourning.

Awareness raising: Child-Help wants to shake up the world to make it aware of this underexposed world health problem.

It is an ambitious plan for a small NGO which survives through the generous gifts of many donors. We could not do it without them.

Pierre Mertens
President Child-Help International
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A photograph of a woman sitting on a hospital bed with two children. One child is lying down, and the other is sitting up. The woman is looking towards the camera with a serious expression. The background shows a hospital room with medical equipment and a window.

What does **hope** mean when the circumstances seem hopeless?

HOPE THROUGH CONNECTION

FALSE HOPE

25 years ago, in Dar Es Salaam (Tanzania), I saw mothers with children whose heads were steadily growing, waiting passively and resigned in the government hospital.

Why weren't they shouting in the hallways so that the voice of their child could be heard?

Why didn't they try and shake this rusty machine that the hospital turned out to be into motion?

I do understand how difficult this is. When I, a long time ago, as a father on a Friday night in Europe tried to move our hospital into action as a shunt operation failed, I also didn't succeed in getting the slow institute to move. Liesje went into a coma and died a week later.

I sat down on the floor next to these mothers and listened to their stories. Their quenched hope was the result of a very long road full of agony.

That they were still sitting there was already an act of heroism. After a while most of them disappeared with their child and never came back. They were not even accounted for in the hospital statistics. Sometimes their languishing hope got a small boost when a nurse stopped and looked at them with tired eyes. I managed to speak to one of the surgeons in the hospital and asked him why nothing was done for these mothers who were waiting. 'These children are getting sicker every day and their disabilities are getting worse'. 'We don't have shunts' said the surgeon with a sigh. It was a hot day in September. 'I have some shunts in my hotel room. If I bring them to you tomorrow, can you operate?'. 'No, our budgets for carrying out operations have run out. The government doesn't allow us to operate anymore this year'.

Nobody had told these mothers: 'go home, we can't help you anymore this year, the budgets have run out'. The hope of these mothers was maybe heroic but in these hospital corridors it was false hope.

What does hope mean when the circumstances seem hopeless? Hope is sometimes like a virus that mutates to survive. For philosophers like Nietzsche, Camus and Sartre, hope is a way to deny our existence. They regard hope as a kind of passive attitude through which life is endured patiently. They make a plea for a life where one takes his or her own full responsibility. Take the helm in your own hands instead of laying your destiny in the hands of hope.

UNDERGROWTH


Beza from Addis in Ethiopia also camped for three months in the corridors of the Zewditu hospital with her baby who has spina bifida and hydrocephalus. After the delivery she was told that her baby had died. On their way home they were told that their son was still alive. They returned to the hospital and took him to another referral hospital for further care and called him Lazarus. He who rose from the dead. In the hospital she saw that his little head was growing every day and because of a clamping in the small brain he acquired several additional disabilities. Both his arms are now rigidly tense, and his neck cannot support the weight of his oversized head any longer. He can't sit up on his own and there is no language development.

Beza and her husband went through a very hard time. After a year they changed their sons name into Hizkiel. This means: 'God looked at a place covered in dried up bones and from there a large nation developed'. 'Dried up bones' might be an macabre image from which we prefer to look away. It reminds me of the work of Berlinde De Bruyckere at the Venice biennial. The artist enlarged a bundle of undergrowth to a 20-meter-long aesthetical sculpture of scars, bones and bloody bandages. She forced the spectator to become the size of an ant and astonished him or her through an extreme aesthetics of suffering. Coetzee wrote the following words: 'We don't look at scars, which are places where the soul has tried its very hardest to come outside but has been pushed back, locked up and sewn inside'.

The world looks away from this suffering. Berlinde De Bruyckere and Beza took it as a starting point for something beautiful. For Beza and her husband the name change was a huge step. No passive hope for healing but a new start from the point where they were now standing. Their beloved son was the victim of a failing health system. They overcame their pain and outrage and saw in their child the invitation to work for him and others. They started a self-help group for the whole country and are now delighted with their son. 'If something were to happen to him, we wouldn't want to have missed him for the world'.

Beza chose **HOPE** as the name of her organization as the hope doesn't paralyze her but gives her energy to look for what is still possible for Hizkiel.

Circumstances that often look hopeless, motivated Child-Help to build shelters where stranded mothers of children with a congenital disability could stay. It was the mothers themselves who gave it the name 'House of Hope' and the name stuck.

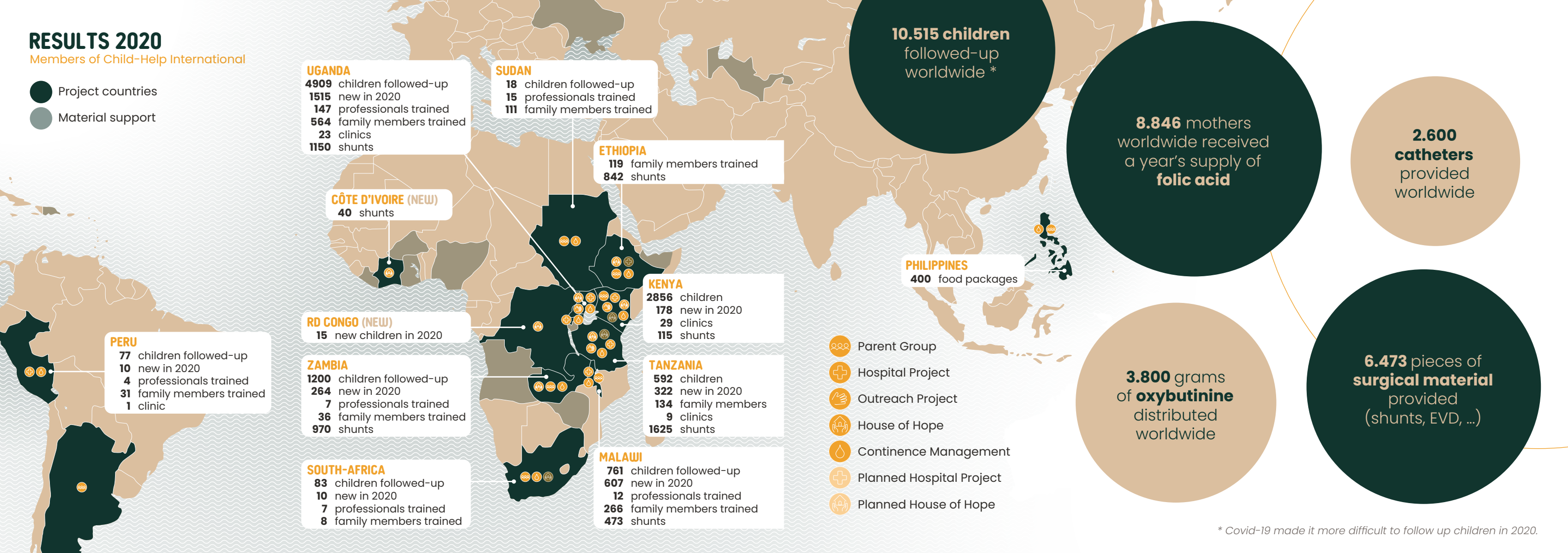


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RESULTS 2020

Members of Child-Help International

- Project countries
- Material support



* Covid-19 made it more difficult to follow up children in 2020.

HOUSES OF HOPE

In 2020 Child-Help started new Houses of Hope with Beza in Addis, one in Kinshasa and one in Abidjan. New houses are in the process of being built near Mwanza and Mombasa and we are planning houses in Zanzibar, Nairobi in Kenya and Kampala in Uganda.



THE SMILE OF GERTRUDE

Houses of Hope want to be a home for parents and children with spina bifida and hydrocephalus. They can stay there before and after surgery. They stay there for free which makes a big difference in their hospital bill. Waiting for weeks for surgery in a hospital bed costs a lot of money. In our shelters they meet other children with the same disabilities. Some are in worse health than others, others are doing much better. They meet adults with spina bifida like Gertrude. Keeping the option open that their child will walk, study and love like them, gives them hope.

These mothers have already travelled a long road before they arrive in our Houses of Hope. They have stood in front of many closed doors. Sometimes roaming the streets for days looking for help. They have lost money to bizarre practices of traditional healers. Many of these mothers have been cast out by the relatives of their husband with whom they lived since the day of their wedding. They are seen as a danger to the whole clan. Ignorance makes them think that they can get contaminated by mother and child and all calamities in the family are attributed to the disabled child.



In our Houses of Hope these mothers with their special children take first place. Their questions are answered and they are being listened to. The Houses of Hope teach the parents in normal language what the disability of their child means. The name of their child is pronounced in a loving way. The smile of Gertrude gives parents a long-term perspective for their child and hope.

Hope is of vital importance for the survival of our children. Even more, who takes away the hope that parents have for their child, kills the child.

Hope is of vital importance for the survival of our children.

HOPE THROUGH CONNECTION

Our Houses of Hope don't give false hope. Correct and fair information is the only thing that you can hold on to and can become a starting point for action. All the rest is quicksand which makes you dependent, scared and insecure. A shunt doesn't heal the brain damage incurred but it makes sure that it doesn't get worse. Parents need to know this. A well-informed mother is stronger, even if this information hits home hard. If a mother keeps on hoping that her child may walk, she might miss the chance to build on his talents. Our staff members are trained to tell the truth, but also to remain close to these mothers to help them to accept them. This proximity is necessary to let the information sink in. We offer someone who doesn't look away from sadness and fear, hope through connection.

The person who cherishes realistic hope and who undertakes action to make it happen, transforms hope into belief. Believing in your child is more active than hoping when a nurse in a hospital corridor looks at you through tired eyes or the false hope that denies reality. As the staff of our houses work closely with the hospitals where treatment is possible, we can act as the advocate and guide for mother and child and speed up tests and surgery.

In Dar es Salaam children are now treated in time. Even more so, the head of the Neurosurgery department is an active volunteer in our network. This is the result of generations of parents in Tanzania who have fought. We can say with certain pride that Child-Help has made a real difference in East-Africa throughout the years. However, we are not there yet, not by a long way.



HOPE IN HOPELESS SITUATIONS

The House of Hope in Kinshasa receives mothers of children with spina bifida and hydrocephalus in a town where access to care is really nonexistent. Certain surgeons dare to ask two thousand euros for a shunt surgery, shunt and scans not included. Parents who can afford this travel abroad for the treatment of their child. The others come to the House of Hope which doesn't have funds to pay for this surgeon. Every year in Congo four to six thousand babies are born with spina bifida and probably double that number with hydrocephalus. Even if Child-Help would give all her funds available, it wouldn't be enough to alleviate the need in Kinshasa. We would support and feed a corrupt system. It would be trying to empty the ocean with a thimble. What can our House of Hope mean in this town of millions where corruption is rife and the chance of treatment is practically nil?

Do we give these despondent mothers false hope when we give them shelter without a chance of treatment? No, we don't as our mandate is not to take over the health care system of a country. We don't promise treatment or surgery in Kinshasa. We support these mothers as there are quite a few things possible without surgery. We stay close to them in the most inhumane situation in which they are the victim of a failing health care system. In the House of Hope these mothers find understanding, someone who stays with them in the deadlock and who doesn't walk away from their pain.

A meal, a bed, a smile and a shoulder to cry on. It was Karine, a mother born in Congo, now living in Brussels, who has an adult son with spina bifida and hydrocephalus, who contacted us to do something for our fellow sufferers in Congo. Because of her great involvement Child-Help dared to take the step to start this house in Kinshasa with them. You understand how difficult it is for her to not immediately start looking for the two thousand euros to pay the heartless surgeon who wants to enrich himself to the detriment of the penniless mothers. In no time dozens of mothers with their dying children would start hoping again.



False hope though. Child-Help encouraged Karine to continue with the House of Hope. Until recently these children and their mothers disappeared into the darkness of their hut, hidden from family and neighbours.

Child-Help wants to give parents a face and a voice with these Houses of Hope.

It is a worldwide problem. Every day, mothers in the Philippines, tired of fighting, post on social media about the ever-growing head of their child. It is the same hopeless feeling that prevails in Kinshasa and unfortunately in most developing countries. And then the only hope for the child is the close proximity of the mother. This proximity the mother at her turn finds in the Houses of Hope.

In the meantime, Karine found a surgeon who operated for free on fifty children last year. Her whole budget went to non-essential scans. Together with her we look into what can be done for children when surgery is not an option and how in cooperation with the hospital, we can avoid the cost of unnecessary medical imaging.

HOPE FOR CHANGE

And so, we take little steps. There is a lot of immense work to be done. The Japanese writer Haruki Murakami wrote that when the mountain of problems becomes too big, you lose all courage and hope. He advises to start with clearing the edges of the mountain. This is what our Houses of Hope try to do. Receiving mothers at the end of the despair. A journey starts with a first step.

Here in the North, we shout out for the need of these mothers by organising exhibitions and letter writing campaigns. In the South we bring parents together. On the 25th of October, World Spina Bifida Day, in many African countries mothers and their children proudly walk the streets from the hospital to parliament. Ministers surrounded by mothers and their untreated babies promise change in front of the cameras. Sometimes these are hollow words, but this is not always the case. In Dar es Salaam, Lusaka and Kampala our kids in government hospitals are treated with our shunts. That is a hopeful sign for sustainable change.





COLOPHON

The financial report can be requested
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