

### HODI TANZANIA

**ANNUAL REPORT 2019** 

Cellebroersstraat 16 - 1000 Brussels

WWW.CHILD-HELP.INTERNATIONAL



### **FOREWORD**

### SPINA BIFIDA AND HYDROCEPHALY UNDEREXPOSED

I am writing the introduction to this annual report while in lock-down, as the world has come to a standstill because of one virus. Corona exposes the inequality between poor and rich, between the Global North and the Global South.

Staying home in a house with garden is different than doing this while living in a one room apartment, a nursing home or a hut that you share with three generations. How do you practice social distancing in the slums of Nairobi or in a refugee camp in Lebanon? How does a mother with a sick child reach the hospital when all public transport in Uganda has stopped running? Our target audience in developing countries is therefore badly hit. Our Houses of Hope to shelter parents and children before and after surgery had to close, parents and children are back on the street. Even without a pandemic, spina bifida and hydrocephaly have no priority in these extremely busy hospitals. So it's waiting for Godot.

Covid-19 puts everything on edge. Very much on edge.

Without wanting to put things into perspective, I do find it strange that this problem brings the world to a halt while chronic health issues like spina bifida and hydrocephaly, which cause more deaths than Corona, stay underexposed.

We estimate the joint yearly incidence of spina bifida and hydrocephaly to be around one million new cases, of which we find the big majority in developing countries where only a fraction of the patients have access to lifesaving surgery. The majority dies a slow death in the darkness of shabby huts and most don't even enter the statistics. One million is a number that is hard to prove as there is hardly any registration in the Global South. Child-Help has been wondering for years how this world health problem can be brought to the attention of society, however the world press seems to turn a blind eye to it.

Underexposed was the title of our photography exhibition in Museum Dr. Guislain in Gent, Belgium. Seven young photographers who visited our projects, showed us images of our work in the Global South. Opinion maker and psychiatrist Dirk De Wachter, who had already promised earlier to be ambassador for Child-Help, opened the exhibition. He visited our projects in the summer of 2019 and wrote a daily column about it in a newspaper. We gathered these reflections of an outsider here in this annual report.

In 2019 Child-Help opened 'Houses of Hope' in Kinshasa and Lusaka, donated 5000 shunts and could, with the help of thousands of donors continue with the commitments we had entered into. More and more Child-Help is moving its administration to the Global South, with its regional office in Dar es Salaam, the creation of a Child-Help department in Tanzania and the affiliation with organizations in Zambia, Kenya and Malawi. Child-Help wants to take its responsibility regarding the fight against global warming by limiting its journeys by plane.

When traveling is necessary we compensate it ecologically and invest in sustainable agriculture. In the middle of this annual report you will find an overview of our results.

Together with you, I hope to survive the Corona pandemic in good health so that together with our loyal donors and partners in the Global South we can continue to build a better world and a more just distribution of means. Because every child has the right to a fairer start in life.

Pierre Mertens
President Child-Help International
www.child-help.international

### **HODI TANZANIA**

Psychiatrist Dirk De Wachter traveled through Tanzania for two weeks in order to visit Child-Help projects for spina bifida and hydrocephalus. In a daily column "Hodi Tanzania" in the Belgian newspaper de Standaard he took you with him on that journey.

**Hodi in Swahili means "may I come in?".** Every year roughly one million households are being confronted with these handicaps. To point out this world health problem, which only receives marginal attention, Dr. De Wachter promised to be the patron of Child-Help and visit these projects in Tanzania.



### A PAINLESS INJECTION

For the vaccinations needed for a trip to Africa, I am sitting in the waiting room of the Tropical Institute, the renowned center that is housed in one of the most beautiful Art Deco buildings in Antwerp.

It gives me a special feeling to know that back in 1986 my uncle was also waiting here for the same injections. He went to Congo by boat as a missionary to build schools and organize education. He stayed there for many years and didn't even come home when his parents passed away. My uncle wrote long letters which took many weeks to reach their destination in Belgium. I found them when my own parents died. I have always admired his drive and commitment.

The flight to Tanzania took a couple of hours and I plan to visit a number of projects about which I reported on a daily basis. The ideas about aid to the third world have fundamentally changed. The paternalistic model in which the rich North brought civilization and conversion is outdated.

I am curious to see how people can connect and foment humanity with the limited resources they have. We ourselves may also learn something from these efforts.

Child-Help attempts to organize help for children with spina bifida and hydrocephalus, where focusing on strengthening self-help groups and supporting local initiatives are crucial elements.

The waiting room in the Tropical Institute is crowded with a colorful mix of people. I am listening to an exotic rhapsody of incomprehensible languages.

Children are walking back and forth or are seriously drawing pictures. Unlike many other people in waiting rooms, these "patients" are not sick. On the contrary, they are looking forward to distant lands, as foreign visitors or as returning residents. **The atmosphere in this room makes me hopeful. In the chaos of major differences, it still seems possible to exist together.** Perhaps in addition to a tour of the nearby Dossin barracks, the justice of the peace could also impose a visit to this waiting room as community service against possible racism.

I am almost disappointed that I don't have to wait long. The doctor tells me that this work almost feels like a hobby alongside her busy general practice, which I believe. I rarely received such a painless vaccination.

### THE DIFFERENCE BETWEEN LIFE AND DEATH

Today we had to hurry to get to our destination on time to participate in a fully planned program. Everything had been tightly arranged and timing was strictly adhered to.

We first visited the Bugando Medical Center, a large university hospital in the North of the country. The patients who are cared for here sometimes live up to 1000 km away.

We primarily focused on the pediatrics and neurosurgery departments where children with spina bifida and hydrocephalus are treated. The 6 neurosurgeons are trained in foreign medical centers and schools. They operate on up to 600 children per year. We were enthusiastically shown around in the wards with dozens of children, sometimes two in one small single bed.

To me this was a huge change: the difference between the hightech equipment we know in Belgium and what is being used here is huge. Yet this visit did not encourage compassionate compassion. The mothers, who often wait here for surgery with their sick children, radiated a dignity that silences!

We saw babies with very large heads who were cherished patiently and lovingly.

Some mothers told us their stories which they did without being tearful about it. Without exception, they were grateful that there is still a possibility to get help for their child. They were patient-a mixture of ill-fated acceptance and hopeful perseverance that we no longer seem to have in our Western society. The mothers seem to find support and connection amongst themselves. From our perspective, they have no privacy whatsoever.

We wandered through corridors and waiting rooms dominated by a colorful bustle. Somehow it seemed to work. We passed through the renovated operating theaters where the doctors proudly explained future possibilities.

They showed the state-of-the-art ultrasound machine that was donated by Child-Help. Thanks to that machine, children's heads can be examined much faster and cheaper. It sometimes makes the difference between life and death. There is a waiting list for the scan. Despite their limited resources, people will have to pay this examination out of their own pockets. That information put our feet back on the ground!



### HOUSES OF HOPE

During the visit to the University Hospital yesterday, it was not difficult to appreciate the benefits of our Western system.

The enormous technological achievements and the highly developed social security system are accomplishments that people here can only dream of. These achievements sometimes seem to miss their goal – dehumanization is lurking around the corner. However, we have to safeguard social security and solidarity is not a definite fact.

Today we visited another project: **The House of Hope.** These are bottom-up initiatives in which mothers and children are cared for in homes, before and after the medical intervention. The welcome was special. All mothers were sitting in the living room with their child and told their personal stories. The power that radiated from this meeting is hard to describe. Medical practice is more than scientifically justified interventions. The level of humanity I felt in this special house I am more than willing to take to our own rich regions and use as a model for our care system.

An important condition for such a model is that experienced experts and family members are to be involved.



We must dare to trust their vision and determine and adjust the policy in consultation with them. The feeling that you are able to help shape existence gives a high level of strength.

**Small scale** is a second crucial point. People can only live together in a homely atmosphere if there are sufficient and adequate care facilities available.

A third point is in line with the latter: **there must be an atmosphere of habitability,** for instance a house in a village without a stigmatizing appearance, where people are not "disabled", but can be mother and father and friend and neighbor. A fourth point is to be able to work with and within the existing medical framework as well as community life.

For many years I have been working in Belgium to take care of people with serious psychological vulnerability putting them in houses that adhere to the above principles. This often results in practical and economic problems.

I saw how this beautiful house in Tanzania realizes this objective. We were received with a pride that really affected me. These mothers had cooked for us like no top restaurant could. Meanwhile, the noisy life in the house gradually dies away. The stars are sparkling in an open sky.

### THE GIRL WHO WANTS TO BECOME A GRANDMOTHER LATER

Today we did home visits and were able to get acquainted with the actual environment of children with spina bifida.

The distances are tremendous on substandard roads. Often, we are on the road for hours to reach the remote homes. Fortunately, we have a driver who would do well in the Paris-Dakar race, navigating between sharp rocks on the sandy roads that barely distinguish themselves in the overall landscape. We admire the panoramas that we know from glitzy tourist brochures. This is indeed a country with beautiful nature.

After some searching, we arrive at Alice, an 8-year-old girl who lives with her grandmother. Because the grandmother has gone to the city, we ask the many relatives and neighbors that stand around, who is taking care of Alice. Our visit has caused a lot of anxiety.

Alice has difficulties walking, so going to school is not easy.



The school is more than 3 kilometers away, an hour's walk for her healthy brothers and sisters. She would have been helped tremendously with an adapted wheelchair that she could operate herself. Going to school is very important to these children and Alice appears to be better at reading and writing than her mischievous brothers. When I ask her what she wants to be later, she says without hesitation: "grandmother".

Her atrophic little legs are very vulnerable and paralysis and sensory disorders easily cause ugly injuries. A highly specialized doctor cannot do much here. My wife is a doctor. Just like in Belgium, the general practitioner is also the most important link in medical care.

In consultation with the home nurse, she can examine the injuries and provide important advice with very simple means. The hygienic conditions are not favorable and that is no exaggeration.

Alice skillfully crawls across the dirt floor where the pets sniff around ass well. Motivating parents and/or grandparents to learn simple wound care is an important task for care providers. In this case, Alice herself seems to understand best what needs to be done. Not an easy task in homes without running water or electricity. Maybe she can also become a nurse or doctor later.



We then pay a visit to 11-year-old Robert, who has major problems with self-made continence material. However, a couple of parents have shown creative solutions.

We continue our tour through the country. The sun sets and we arrive at Nicolas who suffers from serious bedsores that need to be addressed urgently.

Despite or maybe even thanks to these precarious medical circumstances, conversations and contacts develop with an incredible authenticity that you can never will feel on other types of visits. Care often gives access to the real person and that is no different in the rich West.

# A PLACE FOR THE FORGOTTEN CHILDREN

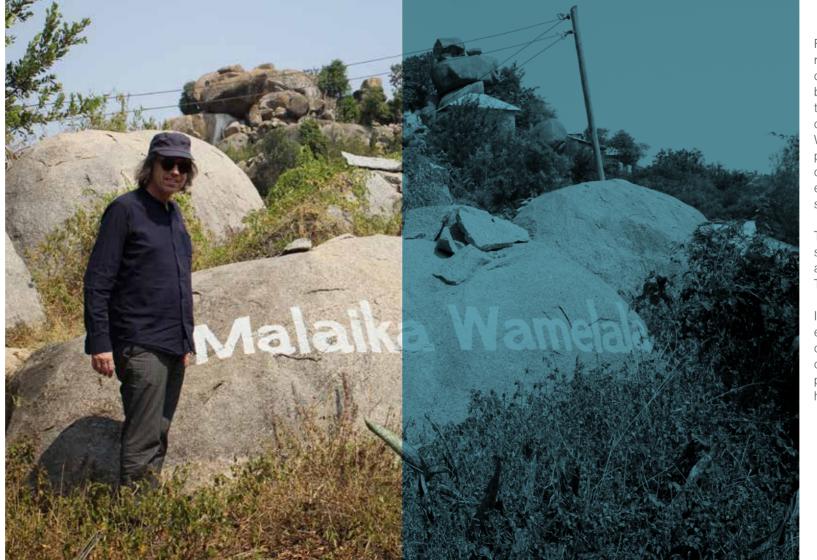
Cemeteries teach me a lot about the differences between cultures.

Today we visited a place where children with spina bifida will end up after they pass away.

This is an initiative of Child-Help, based on the idea that those children are often forgotten when they die. They sometimes die right after birth, when they do not have a name yet ending up in an anonymous non-existence. I hear harrowing stories about children dying due to hospital complications.

Their bodies will not be released if the bill is not paid.

Their remains are disposed of together with the so-called surgical material. Even children who die later often do not get a worthy grave. They are expelled by the family together with their mothers. As a result, they do not have sufficient financial options.



From my experience as a psychiatrist I know that people need rituals and meaningful frameworks to go through a grieving process. Pierre Mertens, director of Child-Help, knows that too. His background as a psychotherapist and visual artist inspired him to create a place on the site of the existing cemetery. It consists of a whimsical rock formation that is characteristic of the North West Tanzanian landscape. On these large stones, reminiscent of prehistoric menhirs (large stones), family members can place their own stone on which the name of their child is modestly painted. Nevertheless, there is a memorial site embedded in the landscape. It costs almost nothing.

This initiative started a few months ago and dozens of name stones have now been placed. We walk further around the site and see simple graves, sometimes just a pile of earth with stones. This really is a poor country.

In the rich West, we sometimes forget the dead. In our triumphant enjoyment of the pleasant life, sadness and loss threaten to be denied and oppressed. As I make that thought, I see a row of children in uniform walking quietly between the headstones. It is past school time. Young life and death seem intertwined. Such is human destiny.

# RESULTS 2019 Members of Child-Help International PHILIPPINES

9803 mothers worldwide received a year's supply of FOLIC ACID

### 9448 CATHETERS

4500 grams of OXYBUTININE

5246 pieces of SURGICAL MATERIAL provided (shunts, EVD, external reservoirs, ...)

PERU

502 children followed-up

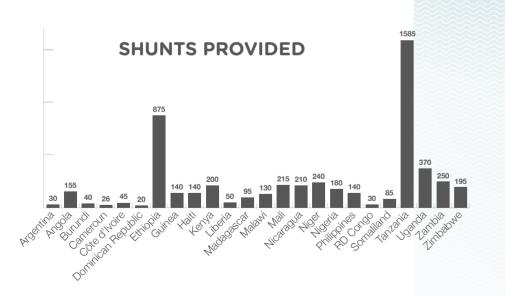
11 professionals trained345 family members trained

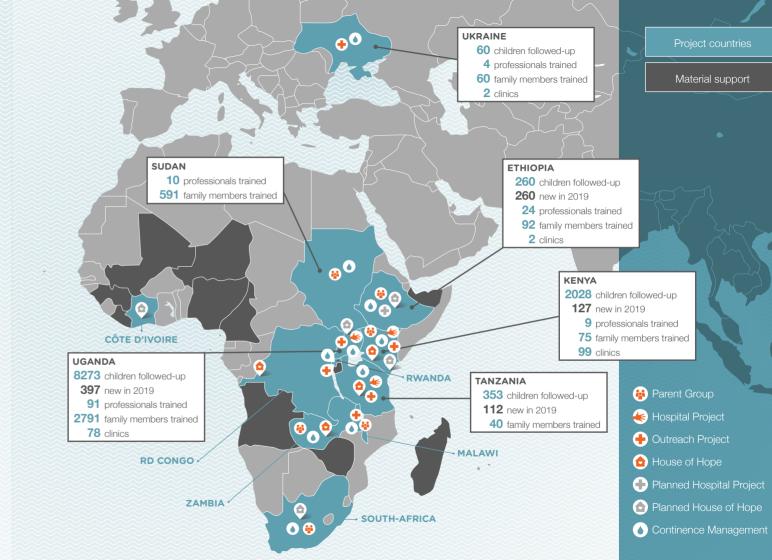
**9** new in 2019

6 clinics

ARGENTINA

Y





# ADORABLE CHILDREN IN MISERY

Mentally spoken, the days were very tiring due to the many impressions left by small children with severe disabilities, of concerned mothers and of courageous helpers in a beautiful country where the limited possibilities sometimes make these people powerless.

In order not fall into the trap of uncritical "rescuers" fantasies, a little distance is sometimes called for. How can we continue to think rationally when looking at cute children in misery? How can we remain sensitive and humane in this world of complex international interests?

We take a day off. I am sitting under a big tree and read a small book. Good literature can grasp the world in a way that is impossible in scientific texts. The subjectivity of man comes into its own more than in statistical analysis that are of course also necessary to form a judgment. That is why I always let my psychotherapy students read a novel.



I myself am reading Impatience of the Heart by Stefan Zweig, one of the greatest German-speaking writers of the first half of the twentieth century. Coincidentally, the book is about a complex relationship between a young man and a severely handicapped woman. His masterful analysis of compassion makes me think about the usefulness and disadvantage of providing assistance, both in these distant countries and in my own practice at home. What actually drives us to do this? Is this useful and is utility a correct parameter? Is some help not counterproductive? How much distance can we keep without falling into an attitude of indifference? How much proximity can we achieve without loosing ourselves entirely? What is the point of all this?

### How much distance can we keep without falling into an attitude of indifference?

I quote Zweig literally: "pity – beautiful! But there are two types of pity. The one, the weak and sentimental kind, is really nothing but the impatience of the heart to free itself as quickly as possible from the painful feeling that comes over you when seeing misery of another being, that kind of compassion co-suffering is purely an instinctive defense of one's own soul against the suffering of another. Then there is the other kind of pity, the only one that really matters: the unsentimental but fruitful pity, which is conscious and which resolutely patient with limitless endurance."

I humbly bow my head to these words. The tropical sun sets gloriously beyond the horizon. A strange bird whistles in the distance.



# WHEN YOUR PARENTS HAVE HIDDEN YOU FROM THE OUTSIDE WORLD FOR 10 YEARS

We are visiting initiatives spread throughout the country. This means we sleep in many different locations. Today we are guests at the Onsea House, a lush lodge with panoramic views of Mount Meru.

Axel is our host, a flamboyant Flemish individual who settled here more than 10 years ago. He speaks Swahili with an unmistakable Flemish accent. In his native language, he tells us how, as a chef, he set up a business employing street children to prepare Belgian-Tanzanian dishes. This is how some Safari tourists get to know the country: wellness, luxury, delicious wines and gourmet dishes. This is a journey of contrasts!

Here we meet Gertrude, a beautiful young woman who wants to share her experience about her life with spina bifida. She has dressed for the occasion. Thanks to the good care of an aunt, she was able to undergo surgery after birth. However, after the surgery she lived hidden in her house for ten years. Her father was ashamed of her disability, she could not walk and even the neighbors did not know a child lived next door.



At the age of ten, after her parent's divorce, she was allowed outside. She went to school from then on and turned out to be a good student who was determined to shape her life despite the difficult circumstances. That still remains very difficult. Her father returned home but is very ill and as a consequence there is no money left for her studies. She studies social work and later in life she intends to use her experience to assist other people.

Currently she is stuck because she cannot pay the exam fee.

I am about to look into my personal finances to help but then realize that this is not the best way to help her. Pierre Mertens, the director of Child-Help, knows that. A better option would be to involve Gertrude in the operation of Child-Help. For example, she can work part-time for the organization and pay for her studies herself.

Gertrude is given the prospect of a suitable job, as she has always dreamed. This is what aid should do: let people use their own powers so that they can take control of their own lives again.

In the evening we have dinner on the terrace overlooking the hills. The people working for Axel serve us with justified pride. **Believing in people can make a difference.** 

### MIRACLES HAVE NOT LEFT THE VILLAGE YET

In between the more formal visits to hospitals, health centers and policy entities, we are trying to make time for ordinary people. It will make this trip special.

One of the most remarkable figures is a man called Hans (some names are echoes of the German colonial past). The search for his home turns out to be quite an adventure. We drove lost in the dusty countryside over impossible roads. These places cannot be found on Google maps, so you will not spot any tourists here.

Eventually we meet on the village square, where Hans runs a small store. He approaches us in his wheelchair with a speed that would beat Marc Herremans in a sprint. The smiling man likes to tell us his story.

"He did it all himself", his parents say with restrained pride. Hans is 38 years old and has spina bifida. His parents thought he would die soon after his birth. However, he stayed alive like a miracle and was able to receive the necessary medical care on time. Both his parents believed in his options which enabled him to follow a training as a shoemaker. He turned out to be a handy man who, in part due to his good social skills, was able to gain a respectful place in the community. He got to know a woman and is now the father of a big three-year-old son.

The entire family poses for the photo session. They are proof that a loving framework is necessary for the future of a child. A close bond, trust and a fundamental belief in the future sometimes tend to mend hopeless situations. This secure attachment forms a sustainable breeding ground on which a life can develop. "He did it all himself", his parents say with restrained pride. I haven't seen his handicap for a long time", his wife says thoughtfully. The son sits on his dad's lap. A good future is in the cards for the next generation.

The love between people can be more powerful than fatal setbacks, a fact that applies equally to our own culture. Miracles don't fall from heaven; they happen in the hearts of good people.



### A SOLIDARITY NETWORK

This long trip also takes us to Zanzibar, the legendary island with a mythical appearance. The atmosphere is very different than in the Tanzanian interior.

Here tourism dominated the endless white beaches, making it an extremely romantic travel destination. But its history is fraught, as an important transit place for the slave trade and as the backdrop for an age-long struggle between various rulers. The town of Stone Town exudes that historic atmosphere, with its beautiful buildings in which Portuguese, Indian and British influences can be found. Yet the Arab influence is the most striking. Except for the tourists, the women are veiled here and the schools strictly Islamic.

As planned, we visit the main hospital. To my surprise it has the most modern equipment, thanks to generous sponsors from Spain and the United States, among others. Cuban doctors are an important part of the medical staff. In their immaculate white robes and headscarves, the enthusiastic nurses look like the sisters I remember from childhood, in the hospital where my late father worked.

In the neurosurgery department a small child with a large water head lies in a spastic position. It appears to be a palliative situation; the child will certainly die. The mother remains at his bed-



side. I carefully ask her how she feels. She answers my questions without hesitation. She feels very supported by the other mothers in the room. Together they form a kind of solidarity network that works unusually powerful.

God is also very present here. He wanted it to happen that way and man accepts his will.

It appears to be a palliative situation; the child will certainly die. The mother remains at his bedside.

I do not get many answers to my questions to the doctors about the possibilities of palliative sedation. That way of working is not practiced here.

The image of the child does not leave me. There is no alcohol in the hotel. I sit in the sand with my loved one and listen to the eternal rustle of the ocean.

# DAILY BREAD WITH A LITTLE EXTRA

Dar es Salaam is the most important city of Tanzania. It is a fast-growing metropolis with huge office buildings where entrepreneurs, bankers and expats occupy their offices.

Millions of people crawl through the streets in a colorful mix. Businessmen in three-piece suits, women in burka, Masai shepherds in their traditional clothing, young people in fashionable outfits, children in school uniforms. As in many places in the third world, urbanization is unstoppable. Young people move en masse from the poor countryside where they see no future. This results in enormous challenges for policy makers. The contrasts between rich and poor are enormous.

Today we visit one of the most important companies in the country, a large grain mill. The link with Child-Help requires some explanation. Spina bifida is a condition that occurs in the first period of a pregnancy, when the nervous system is developed. Folic acid plays an important role in this period. In our regions, folic acid usually is prescribed to women who want to become pregnant. This is not the case in most developing countries.

Moreover, the daily diet is often one-sided and limited. As a result, the risk of a disability is significantly higher. One of the ways to take preventive measures is to enrich basic foods such as bread. Bread is being used more and more every day by the urban population. Therefore, adding Folic Acid to flour is an interesting way to reach large groups of the population.



We are welcomed with due respect in the impressive offices of one of the richest industrialists in Africa. We get detailed information about the production process. Thousands of tons of grain are milled every day and huge trucks are constantly coming and going. The founder started out as a poor potato seller in the sixties. His company now has an annual turnover of more than 800 million dollars. The tour of the factory is both funny and confusing to me. I imagine King Philip and his entourage often are shown around that way. It is important that the company has registered the addition of folic acid in its mission. The big boss has not forgotten his background.

In the evening we are the guest of the mother and aunt of our guide. Thanks to that wonderful man and his wife we were able to visit untraceable places. They arranged, negotiated and organized everything for us with an untiring energy and efficiency that turns every caricature of Africa upside down. We spent hours in a traffic jam before we reach the distant suburbs. The two women welcome us with a royal allure, with a combination of dignity and simplicity that no company can compete with.

### **BRAINDRAIN**

This is a journey with many special experiences. It is already 35 years ago, during the neurosurgery internship of my medical training, that I was once again standing, wearing a surgeon's dress, in an operating theater.

The reason was a visit to the MOI Hospital where Dr. Shabani has specialized in treating children with hydrocephalus. Just to-day there is a conference going on with participants from all over the world. I speak with an American neurosurgeon from Columbia University who explains that they have the most experience here in this hospital, with more than 800 procedures per year. The endoscopic device and the shunts, an artificial connection inserted in the body, for example to drain off excess brain fluid, are supplied by Child-Help. As a result, everyone here addresses director Pierre Mertens as "Mister Shunt".

We follow the procedure on the spot. The technology that was partly developed here appears to have become a reference technique, even in the most advanced Western hospitals.



#### **NEW YEAR'S RECEPTION**

Sometimes experiences from developing countries can also influence policy in our world. Extensive research has shown that inexpensive Indian shunts used in Africa produce equally good results than the 25 times more expensive ones from America. However, in order to substantiate that fact scientifically, research is needed for which there is hardly any funding. Ambitious doc-

tors are attracted to centers with more options such as exist in South Africa and the USA. This causes a brain drain; this time without a shunt.

Busy day today, we meet with managements, social workers, parent groups, Government departments. I shake more hands than at a New Year's reception. Everywhere there is an atmosphere of enthusiasm about what has been built-up over the past 20 years. This is a public hospital where children up to the age of 5 can be helped free of charge. The Government invests a lot and the President's portrait hangs in almost every room.

#### SUPPORT FROM CHINA

With Dr Shabani I speak more about the future of the country than about surgical techniques. He explains that the President is trying hard to curb corruption and is investing in new roads and public works.

There is a lot of foreign support, often from China lately. It remains a very difficult exercise not to fall into the trap of neo-colonialism while maintaining dependence and inequality.

Only everyone's own strength can be strengthened with mutual respect for differences so people can work in the right direction with patience and trust.

Awaiting my return to Belgium, I try to figure out what was most essential now, in this tiring multitude of impressions. I end up with Impatience by the Heart by Stefan Zweig, the book I read this trip. Fundamental things transcend time and place, he says: "Only when you know that you also mean something to others, you feel the meaning and purpose of your own existence."



### COLOPHON

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

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