

A photograph of a woman with dark hair, wearing a white floral-patterned shirt and blue pants, sitting on a bed and holding a sleeping baby in her arms. The baby is wearing a yellow long-sleeved shirt and blue pants. To the right of the woman, a young girl with dark hair in pigtails, wearing a pink long-sleeved shirt and patterned pants, is sitting on the bed looking towards the camera. The background shows a simple room with light blue walls and a wooden window frame.

CHILD-HELP
INTERNATIONAL

ANNUAL REPORT 2018

A FIG LEAF

THE SIZE OF A BUSINESS CARD

Cellebroersstraat 16 - 1000 Brussels

WWW.CHILD-HELP.INTERNATIONAL



FOREWORD

Together with you, donors, specialists and partners, Child-Help is fighting against the inhumane injustice that hundreds of thousands of children with Spina Bifida and Hydrocephalus undergo every year in developing countries.

The photographs of Vietnam in this report are from Elisa Maenhout, the eighth Royal College of Arts student who travelled to the Global South and visualized the projects of our local partners. On October 25, 2019, World Day for Spina Bifida and Hydrocephalus, a photo exhibition of all students will be held in the Dr Guislain Museum in Ghent. These photographs give a good impression of life with Spina Bifida and Hydrocephalus in developing countries. You are hereby invited to visit this exhibition which will be commented by the renowned photographer and teacher at the Royal College, Nick Hannes.

2018, A YEAR OF REFLECTION AND PLANNING

The story in this annual report takes us to Niger, the poorest country in the world where children with spina bifida and hydrocephaly are also being born. It illustrates the great need and explains the cause to which Child-Help is committed.

According to estimates **our target audience grows yearly by one million newly affected children.** These are figures similar to those of malaria. As with malaria, a large majority of children with spina bifida and hydrocephaly live in developing countries where there is hardly any access to affordable care. What can a small organisation like ours do with such a tall order? It looks like an umbrella as protection against a tsunami.

This is the reason why in 2018 Child-Help has made its **mission, vision and strategic goals** clearer and has translated them into a plan that takes small definite steps towards change.

OUR MISSION

Our mission is that every child with spina bifida and hydrocephaly is entitled to qualitative care.

OUR VISION

We translate this into our vision which states that we work together with all our partners to improve the access to care for our target audience. With experts in the South we translate the available knowledge into models and protocols which enable affordable and accessible aid. For this reason, we are building up centres of expertise of sub-areas in care for our children in the South. They act as laboratories for the development of expertise and become training centres for a South-South exchange. Within any of these projects we support the start of self-help groups as they are what it is all about.

OUR STRATEGIC GOALS

The six strategic goals which should translate this are:

Recognition of Spina Bifida and hydrocephaly as a global health problem

Make the already accumulated knowledge accessible for everybody

Continuously improve and expand this knowledge

Make our projects in the south more professional and sustainable

Strengthen our own organisation
Child-Help to be able to deal with this assignment

Expand and diversify the necessary fundraising

NEW IN 2018

SHUNTS AND OTHER MEDICAL EQUIPMENT

Besides the ongoing projects in the South, which we have been able to support thanks to the aid of our loyal donors, many new requests for medical equipment from other countries have been coming in. In 2018, besides incontinence equipment Child-Help donated **3980 shunts in 35 countries**.

To improve the quality of care, our surgeons in the South developed a **protocol to place shunts** in Africa. In Kenya we equipped a workshop with **orthopaedic tools** and provided training sessions for the staff. In Mwanza (Tanzania) we donated an **ultrasound machine** to avoid the cost of CT scans and to be able to check the kidneys. In the MOI hospital we donated a complete **endoscopic installation** for surgery which can prevent the placing of shunts.

COOPERATION WITH IF

Child-Help originated from projects which we were able to start in the nineties with the aid of Norwegian funds within IF. At the world conference in Delhi, **IF and Child-Help signed a cooperation agreement** which stated that Child-Help would take over those IF projects in East Africa which take care of the direct services to our target audience. In the countries in the South where IF is active, IF will continue to support the self-help groups.

EDUCATION AND TRAINING SESSIONS

In 2018 Child-Help actively started the search for **additional experts** who could take care of the growing demand concerning the management of incontinence. An information day already resulted in three new teams which in 2018 provided training sessions for care providers from Kenya, Tanzania, Ukraine and Zanzibar. Child-Help experts joined an IF work group which, commissioned by Handicap International, prepared a script for the rehabilitation of children with spina bifida and hydrocephaly in Vietnam.

HOUSES OF HOPE

In Mwanza we opened a new successful House of Hope and are working on a script for similar new initiatives. A South-South exchange between the House of Hope in Kijabe (Kenya) and the one in Mwanza was useful for both. Plans for 3 other Houses of Hope are on the drawing board.





FRENCH-SPEAKING AFRICA

Through the commitment of Child-Help France we were able to take our first steps in French-speaking Africa. Child-Help went on mission with Teo Aquitaine in Douala and with Teo2004 in Niger. You can read about the trip to Niger later in this report.

AN OFFICE IN TANZANIA

Child-Help opened a small office in Dar es Salaam to enable us to better follow up and guidance for our projects. FoCC, a Tanzanian organisation for children with Cancer, Spina Bifida and Hydrocephaly is our host in Dar Es Salaam.

RESEARCH

Together with the Bo Hjelt Foundation, Child-Help started a research project concerning intravesical Oxybutynin for the first years of life as well as fundamental research into the causes of both disabilities.

PREVENTION

Last but not least, Child-Help is actively promoting primary prevention. All mothers with an elevated risk of bearing a child with Spina Bifida will get free folic acid and are involved in awareness campaigns in their local communities. On an international basis we co-operate with IF to raise worldwide awareness for Spina Bifida and Hydrocephalus.

Child-Help made a special contribution to the improved mapping of the status of folic acid in Latin-America.

There is still a lot of work to be done. Unfortunately, in a lot of unexplored regions we can't do more than leave our business card.

A FIG LEAF THE SIZE OF A BUSINESS CARD

by Pierre Mertens

In her book “Dead-end Aid, why Aid is not working and how there is an alternative for Africa”, Dambisa Moyo, A Zambian economist makes a painful balance of development aid during the past 70 years. This Aid has failed in many ways and has not contributed to the economic and cultural growth of the African continent.

What is worse, this aid has contributed to the further decline of most African countries.

Her book accompanies me on my way to Niger where the Paris Teo2004 team is organizing a neurosurgical mission at the National Hospital in Niamey. I was in Cameroun with Teo Aquitaine from Bordeaux.

Niger does not have direct access to the ocean. According to the UN index of human development (2013), Niger is the least developed country in the world. The more than 20 million inhabitants depend on the Niger river. The rest is pure desert. Despite the serious food shortages, the country hosts a large number of displaced people fleeing the violence of Boko Haram. The red-brown arid plains are littered with houses that determine the landscape like loaves of bread of the same clay.

This week, after four years of renovation, the colonial museum in Tervuren, Belgium, reopens. This event is accompanied by a heated discussion about de-colonisation, how do you exhibit the mistakes of the past with respect for the people who suffered from it?

President Macron returns stolen works of art to Benin and speaks with the representatives of the yellow-vest movement. They have also become active in Belgium where the government totters due to the UN migration pact.

Together with Dambisa Moyo I am on my way to Niger, where also children with Spina Bifida and Hydrocephalus are born. To keep care and treatment for our children affordable for our children, Child-Help is committed to translating current medical knowledge of local and Western experts into opportunities that are available



in each country. As an alternative to expensive CT-scans, Child-Help purchased an ultrasound machine for the Bugando Hospital in Mwanza (Tanzania). Affordable care saves children's lives, certainly in countries like Niger.

When I arrive, the Paris team has already left for the hospital and therefore I decided to plan an appointment with "Aide et Action". They focus on the integration of disadvantaged children in education. With more than 40 inclusive schools, they reach 1200 children across the country. However, there are no children with Spina Bifida amongst their pupil population. These kids remain hidden, especially because of the problems with incontinence. "When they are dry and clean, they can come to us for education. However, incontinence is something medical that does not fall within our field of work" they claim. "Not even when it comes to integration in education?", I try. "No, that is the role of our health centres and they do not have the expertise" Aide et Action responds. So, also here in this country children with Spina Bifida stay hidden from education.

Aide et Action sees community-based rehabilitation (CBR) as the local pooling of forces of which they are part.

However, this specific expertise in incontinence is not available in CBR either. They suggest contacting Humanity and Inclusion (HI), the former Handicap International, but when it comes to incontinence, HI also will call Child-Help for its expertise.

By changing their name, they have extended "disability" to mean all minority groups in humanitarian aid.



Sadly, our children, who are already excluded everywhere you look will not win.

Large cash-flows go towards humanitarian aid such as famine, refugee camps and natural disasters. However, the Spina Bifida Tsunami of nearly one million cases per year remains under the radar. Cameras cannot get a million hidden families in the picture. Our children do not block the roads wearing yellow vests.

So, here come the health centres. This is in line with recent questions we receive from Tanzania and Ethiopia to support health centres with our expertise on Spina Bifida and Hydrocephalus. Health centres could include a CBR element on medical problems with children with Spina Bifida. Primary care must be closer to the homes of people. We are losing children because of the long distances to available care.

The Parisian Teo2004 group comprises of Oliver, a young retired neurosurgeon, Martine, a neuropediatric, an Electro Encephalography (EEG) technician, a nurse, an anaesthetist and a children's animator. It is their 14th mission in Niger. They have developed a long-term relationship with the hospital which I hope to make use of.



Martine developed a service for epilepsy, donated an EEG device and trained a technician. Epilepsy is a big problem in Africa. Five years ago, Teo2004 funded a playroom for hospitalized children. This time they also brought in 7 large bags full of medical equipment but also with toys for the children.

The neurosurgeon gives lectures and attends the staff meetings. He reacts violently when he hears that a child with a stabilized hydrocephalus will be getting a shunt.

ETV, performed with a rigid scope, also donated by this group, is done under strict conditions in only 30% of the cases. Spina Bifida is a contraindication here.

Professor Samula, head of surgery in the Hospital, is our host. He tells me that the incidence of Spina Bifida is also very high in Niger, but he does not have the exact figures. He receives one to two new children with Spina Bifida every day. There are now 6 neurosurgeons but only one operating room. On Saturdays and Sundays only, emergencies will be treated. We have to be honest he adds, Spina Bifida and Hydrocephalus are seldom seen as emergencies.

As a result, there is a waiting list of more than 200 children, one third of whom die whilst on the waiting list. In addition, the anaesthesia increases the waiting list; a child requires more time to prepare for surgery than an adult and on top of that there is no money to be made treating children. Healthcare up to the age of 5 years is free in Niger, including CT-scans. Samula speaks frankly and does not hide anything.

He studied in France but fights for his country and his neurosurgical department. He tries to avoid that the surgeons he trains will leave the country for a better paying job elsewhere.

When I speak to him about the cost for the patient, he argues to get the country out of poverty. The international food aid demotivates the farmers whilst there is water in the ground so why not invest in improving the supply of water. The old irrigation systems have to be repaired as it only rains two months' a year!

Although care is free, parents have to pay for transport, medication, shunts and miscellaneous surgical equipment. He seems to agree with Dambisa Moyo but is happy with my proposal to donate the shunts.

It seems he has buried his big dream of a neurosurgical centre. There is no money for that now. Expanding and renovating existing ones is more realistic.

Thirty patients are waiting for me on the floor of the paly room. The room is decorated with garlands.

Cherifa, a beautiful 6-year old veiled girl with Spina Bifida, crawls around with a doll on her back, much the same way she is carried by her mum. She eagerly poses for a photo with her older sister. Cherifa means Nobel, Honest and so are her eyes and smile. To my surprise the busy Samula stays with me. Most parents only speak a local language which are all different. The conversation will be facilitated and by three translators and Samula is helping out when necessary.

The fathers are absent. Many of these mothers have been expelled by their community because they believe that these children are bewitched. The devil must have penetrated the pregnant woman because she covered her body insufficiently in public. They believe that the unborn child became possessed as a result. The mothers get the blame and are rejected by many fathers.

I sit down with the mothers on the floor and tell them that I also am a father of a child with Spina Bifida. This birth defect occurs all over the world. You and I are innocent as it is a global health problem. You do not stand alone. There is IF and an entire community with children like ours. I tell them that some of our children are doing well, study, marry and have children of their own. About Margo who succeeded me as chairman of IF. She is a paediatrician in a wheelchair. I encourage them to invest in the talents of their children. There are of course questions about high costs, incorrect treatments and waiting lists.

Cherifa's mother lifts her child and with desperation shows the bedsores on her bottom.

A shocking honesty. A festering wound the size of a child's fist. Another mother does the same thing with her 6-year old son: also, two festering wounds. I tell them that bedsores can be prevented. These children do not feel them but treating them with natural honey will disinfect the wounds and heal them.

In this hot climate with temperatures of 40 C in the shade, these wounds are also caused by the fact that the children are sitting in their own urine and faeces.

Child-Help developed affordable solutions for incontinence. The solution for the incontinence of bowel movements can be learned and does not cost a lot of money. Samula asked me to explain to them how that works. I start explaining about the so-called bowl wash every second day and the need for frequent catheterization of the bladder.

There are solutions and Child-Help wants to introduce them in Niger.

Will my child be able to walk? What about training? Does a shunt remain in the body forever and do you have to catharise for life? I listen and answer the questions honestly. A mother testifies how well her 8-year old child is doing. Hope is on the rise and that is positive. In Niger and many other countries hope is needed to believe in the future of their children.

However, there is also a great sense of expectation coming to me and Child-Help. They felt abandoned by all NGO's and now all of a sudden there is a white man who has experienced the same problems and brings hope and possible solutions. Their stories are universal, their problems unsolved, their hunger for information and hope for change legitimate.

Because of the language difficulties, mothers have limited contact with each other. For them it is difficult to form a group. For Child-Help the commitment of these parents is important. The poorest country in the world, plagued by violence and extreme drought, has a Babylonian language problem and is cut off from the world by its misery. Who is going to Niger these days?





A mother asks “and what now? You have been here so often, and you leave, and nothing changes. I come from very far and what should I tell my husband?”

I am stammering that I am in Niger for the first time. I give her my business card as a means to keep in touch. Her question is very legitimate. She is right, nothing will change here immediately. My business card feels like a fig leaf and does not answer her question “what now”? These mothers stay behind with their children. I am confused and while I am thinking what to say, all of a sudden there is chaos because now everyone wants a business card from me. It looks like a food distribution point in a refugee camp. My cards stand for something. Hope and a desire for change.

The mothers are called away for a clinical examination, but they do not want to leave. Their programme for the day must continue and I leave the playroom quietly.

Samula, who stayed on to the end, is impressed. We have to do something now he says and rather today than tomorrow. We do not discuss incontinence because we do not have a ready-made solution. However, that is their biggest problem. I suggest that he starts looking for a nurse who is interested in setting up an incontinence project here. Child-Help can provide her with material and find a place in Africa where she can be trained. Question is where can she work? “In my department”, Samula replies.

The next morning at breakfast I join the French team and ask how they see our further co-operation. Oliver and Martine are pleased with the interest of Child-Help to include the follow-up in the hos-

pital. They regard us as experts and hope to work together on follow-up. Martine says: “Child-Help must have plenty of experience, how do you do that in other countries?”

Basically, Child-Help deals with a local request from a potential partner. We did not have one in Niger, but now we do. Samula heard the desperate cry for help from the parents. We can also benefit from the fruitful relationship which Teo2004 has built with the hospital over the years.

In the hospital I ask them to allow me to visit the new hospital General manager. It is important to have management with us and not against. Samula tells him the story of Teo2004. We discuss what has been built up with them year after year: EEG, Endoscopy, New playroom, International exchange of students and how Child-Help was added to all of this.

He had heard the cries for help from the parents and that the follow-up of these children, as proposed by Child-Help, can now be integrated into Teo’s work. It seems a logical next step.

Although the nurses and other staff are on strike, Samula has managed to arrange for Teo’s plans to continue. I visit the physiotherapy department where only the head of the department is on duty. The others are on strike.

His department attends many children with Spina Bifida, and he believes that a continence management project can be developed. The location appears to be suitable for this purpose. Two days a week are reserved for children.

Together with Martine I walk through the ward where children who have been operated are waiting for additional treatment. I regret that no paediatrician from the hospital accompanied us. The service would be enhanced with a local paediatrician like Martine. However, the paediatricians mainly focus on malnutrition and infections funded by international agencies. They only show up at neurosurgery when specifically asked.

I am charmed by how the French nurse speaks with love to and about the children. Most of the children are doing well. I see proper medical practice here. In the meantime, the French animator decorates the beds with (unfortunately not latex-free) balloons and the children are handed toys. The mothers chose the colours of the balloons. All whites are left over and rightly so, there is already enough white in the ward.

I speak to the only father present in the ward. He is from Tahoua, a city 500 km from Niamey. He is a teacher and regional representative of this area. His daughter received a shunt and is waiting for a second operation. He paid € 115 for this shunt and has been at the hospital for 37 days, he sighs. The waiting list makes him desperate. Someone like him could inspire an association of parents to be founded. I tell him that I also am a father and that I have learned a lot from other parents in my country. Such an association of parents would also be useful here in Niger. He argues for a more regional approach. The distances are murderous. I plead for local, with three or four families getting together. A small group in the beginning standing up for the needs and rights of their children in Niger. We make a selfie and exchange addresses.

Martine starts her neurological consultations and Oliver commences with an operation. Lectures are planned for the afternoon. After lunch I say goodbye to the French group in Samula's stuffed office. It really is a formidable challenge to be able to make a difference for those parents and a luxury situation to be able to build on what Teo2004 has already realized here.

There is so much to do and so much suffering and injustice that remains unseen.

In the meantime, I read the entire Dambisa Moyo book that is ingeniously written but far too economical for me. She is correct when she says that the decade-long Aid programmes for Niger has not lifted the population out of poverty and may have caused a reality nobody wished and that is that nothing has really changed their situation. She argues that countries should invest in infrastructure that will attract and stimulate economic development. She underlines that humanitarian help has a counterproductive effect and paralyzes the local population. Child-Help and Teo2004 must be on the alert for this. Projects may not fully depend on this. We ought to make ourselves superfluous in the long term, says Oliver.

Dambisa Moyo does not give any clues to the injustices that these mothers are undergoing. Unless a country grows economically healthcare will not improve. The sad fact is that children in

Niger cannot wait for decades for the economic recovery of Niger. They are incontinent under a blazing sun with 40 degrees C in the shade. However, Dambisa Moyo is right, Niger is their country with their elected representatives and their healthcare and especially their children.

I wonder if the renovated colonial museum in Brussels will also pay attention to the "dead-end Aid" of the post-colonial period.





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COLOPHON

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