

The image features a large white circle in the top-left corner containing the text 'CHILD-HELP INTERNATIONAL'. The background is a photograph of a young child being held by a woman, with a puzzle-piece pattern overlaid on the entire scene. The puzzle pieces are light-colored with dark outlines, creating a grid-like effect over the photo. The child is looking towards the camera with a neutral expression. The woman holding the child has her back to the camera, wearing a white top and a pink headscarf. The setting appears to be an indoor space with wooden walls and other people in the background.

CHILD-HELP
INTERNATIONAL

ANNUAL REPORT 2017

WHEN THE PUZZLE FITS...

Cellebroersstraat 16 - 1000 Brussels

WWW.CHILD-HELP.INTERNATIONAL



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WHEN THE PUZZLE FITS...

Child-Help wants to improve the quality of life of thousands of children and adults with spina bifida and hydrocephalus in developing countries. This is only possible through timely detection, the right treatment and proper organisation of life-long care.

Child-Help can not do this alone. That is why 2017, like 2016, was a year of puzzling and networking to put our target audience on the map and find the right partners in our battle.



START AT THE EDGES...

Our experts continue looking for quality, the right approach, and good partners, like the International Federation for Spina Bifida and Hydrocephalus (IF), PUSH, Cure Hydrocephalus, Bethany Kids, the Bo Hjelt Foundation, our local parent groups worldwide, and many others. We also continue the search for sufficient resources to finance the growing needs. Fortunately, we receive the support of thousands of donors, several funds and many volunteers. Without them, Child-Help would never have been able to contribute to the almost **50,000 neurosurgical operations** which we have been able to perform in the past decades.

These fantastic results did not happen without significant effort. Similar to a difficult puzzle with too many pieces, we started at the edges and continued working in the hope that suddenly the puzzle would fit.



PUTTING TOGETHER A STRATEGY LIKE A PUZZLE

As we are closely involved in the care of children with spina bifida and hydrocephalus, and are working together locally with our target group, our approach is mainly determined from the bottom up. Our local parent groups are becoming stronger and clearly expressing their needs and grievances. Child-Help tries to respond to these calls as resourcefully as possible. We also try to improve the way Child-Help works by evaluating our project closely and seeing how we can work more efficiently.

Because of the reinforcement coming from our departments in Germany, France, Italy and the Netherlands, we have to define our work more clearly and streamline our cooperation. We are looking for a way to all work together on the same puzzle. This is the way Child-Help International gradually came into being in 2017. Child-Help actively looked for partners, projects and experts in Belgium, Germany, France, Italy and the Netherlands so that each organisation would get a firm foot on the ground in each respective country. The existing national associations for spina bifida and the professional spina bifida teams are the primary partners for this.

Via the spina bifida teams in France, Child-Help started working together with Teo Aquitaine, which resulted in an operation and prevention project in Cameroon. Sometimes new collaborations come from unexpected places. The story of the German paediatrician Dr. Theresa Harbauer, highlighted later in this report, is a good example.

2018 aims to be a year of consolidation and planning, in which we want to continue to build on our successes and learn from our mistakes.

LAYING PUZZLES TOGETHER

Child-Help also looked for a **partnership with ISCoS**, the International Spinal Cord Society, a 60-year-old umbrella organisation for neural tube defects. After World War II, ISCoS emerged to help the many people afflicted with paraplegia. In the years that followed, they extended their target group to all other spinal cord injuries, such as tuberculosis of the spine, cancer, etc. However, they have never included spina bifida in their target group. We often notice that adults with spina bifida fall between the cracks. The secretary of ISCoS also admitted this, saying, “The paediatric services push them away and at the same time, they are not welcome in our association.” However, after discussions, we came to the conclusion that our target groups have similar needs and questions, and require similar treatment and care. In 2017, ISCoS decided to cooperate with Child-Help and open up their organisation to our target group.

Child-Help also participated in the workshop of **Cure Hydrocephalus in Cape Town** where the close cooperation between both organisations was reaffirmed. Neurosurgeons, Cure Hydrocephalus’ target group, are often Child-Help’s first contacts in new projects, since they order shunts from us. Some of them want to work around prevention or ask for help with the expansion of care and follow-up.

The vast majority of these children are born in developing countries, where most have no access to the necessary care.

At the 10th session of the Conference of States Parties to the CRPD, our president, Lieven Bauwens, representing IF, pleaded for the **registration of children with a disability at birth**. Today, a disability of a child is only registered from the age of two. As a result, there is no correct information or data about children with a congenital disability, since a portion of this group dies without care or attention. However, through our own research, we have been able to make estimations: yearly, between one-half and **almost one million children with spina bifida and/or hydrocephalus are born**. The great majority of these children are born in developing countries, where most have no access to the necessary care. This is what makes Child-Help so relevant. We are outraged that the world doesn’t acknowledge this huge health problem.





Child-Help and our experts are increasingly recognized internationally. On the 20th of March 2017, Dr. Carla Verpoorten received the five-yearly prize for her life-long work on the treatment of spina bifida at the congress of the American Society of Spina Bifida for Research and Care, in San Diego, USA. Her effort to translate expensive Western medicine into cheaper alternatives for children in developing countries was especially appreciated. In her expression of gratitude, she said that the prize might have come five years too early, as her work isn't completely finished yet. That is correct. Dr. Verpoorten and Dr. Van Gool continue working together with Child-Help and the Bo Hjelt Foundation on the scientific research of the treatment of the neurogenic bladder, in cooperation with the University of Essen in Germany and the Red Cross hospital in Cape Town, South Africa.

Dr. Wouter De Groote and nurse Myleen Christiaens have been faithful volunteers of Child-Help for many years. In March 2017, together with IF, they travelled to Vietnam for Handicap International, where they led a workshop regarding best practices in rehabilitation for spina bifida. This resulted in national guidelines and protocols for the rehabilitation policy in Vietnam.

Together with Cure Hydrocephalus, Child-Help worked on a protocol for shunts. A proposal was sent to all surgeons with whom we cooperate, and their comments were incorporated into formal guidelines by which everybody who receives our shunts has to abide. This year Child-Help donated no less than 3900 shunts to dozens of hospitals worldwide. We are also working together with Cure Hydrocephalus on a registration system of children who

have been treated, which would enable us to better evaluate the quality of the surgery.

But the real work of Child-Help is located in the Global South. In 2017 we started a successful continence training session in Ethiopia in cooperation with the local parent group. In all Child-Help projects, we continue working with a focus on the Houses of Hope, parent groups and lifelong care.

In 2017, together with IF, we organised a successful workshop in Mombasa to which experts, parents and young people with spina bifida from all projects were invited. Almost one hundred participants from Nigeria to the Philippines returned home, motivated and inspired to continue their work for our children. The workshop confirmed the special relationship between IF and Child-Help. Child-Help began as a part of IF, but now operates as an independent organisation with an emphasis on care and aftercare. IF is an association of people with a disability, whose focus is more geared towards raising awareness, primary prevention, and defending the rights of those with spina bifida and hydrocephalus. In this way both organisations are complimentary.

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in the Global South.

2017 is also the year of unexpected gifts. To give you an impression, we will take you to Tanzania where suddenly the pieces of the puzzle came together.

WHEN THE PUZZLE COMES TOGETHER DAR ES SALAAM, SUMMER 2017

In Mwanza, in northern Tanzania, we visited a hospital to which we donate 600 shunts a year. Janet and Walter, a couple from Tanzania who care for children with cancer and also engage with our target audience, are the motor of this project. They established FOCC, Friends of Children with Cancer. In the hospital wards where children with cancer are treated, they were confronted with a large number of target group who were waiting for a surgery. This is why they expanded their work to children with hydrocephalus. FOCC works with volunteers who are present in the ward on a daily basis. They have a hospital badge and are allowed go everywhere just like the other staff members. In this way they can guard the quality of care and support the parents.

FOCC started a day centre for parents with severely disabled children, where they can receive physiotherapy and support. Fur-

thermore, it's only two bus stops away from the **House of Hope in Dar Es Salaam**. This is a very positive initiative that relies on Tanzanian volunteers. Sipha, who now works for the Tanzanian parent group ASBAHT, donates her free time to this project. While the children receive physiotherapy the parents are trained in crafting products they can sell in order to start a small enterprise so they can survive financially.

These are initiatives by Tanzanians themselves. The meal is cooked by them and for them, we can only help them to spice up their meal a bit more. We invited FOCC to our workshop in Mombasa to inspire and activate the other parent groups. This year, together with Child-Help, FOCC is planning to start up a House of Hope in Mwanza. With 600 children a year the needs are urgent and high.

Filled with enthusiasm we travelled on to Haydom for a seminar on spina bifida and hydrocephalus. Haydom is a small town in the middle of Tanzania built around a hospital with 400 beds. Norwegian missionaries built it there in the middle of nowhere in the 1960s. Pierre Mertens visited the hospital more than 15 years ago when he was still president of IF. Back then, the hospital had a good reputation and a promising future. We provided them with a number of shunts and organised a continence training session together with our project at CCBRT, at the foot of the Kilimanjaro in Moshi. This modest project was successful for a while, but as time passed, we didn't hear from them again. Until early 2017, when we were contacted by Theresa Harbauer, a young German paediatrician who ended up in Haydom five years ago and worked there for two years. At the request of the Norwegian



then-director she started working with our children and initiated a real spina bifida team. Three years after she left the project we are returning to Haydom. This is exciting, as these initiatives sometimes stop abruptly when the main person leaves or new management takes over.

This initiative from Teresa comes as an unexpected gift from God in our fight for our children. And, Haydom works! More than 40 people attended the seminar and a lot of their children are doing very well. Colleagues from our projects in Moshi, Arusha and the parent group ASBAHT are also there and make a big impression with their engagement and enthusiasm. CCBRT Moshi supported the parents financially by paying back their transport costs. They sent Shedrack Domingo, a physiotherapist and financed the team of Arusha to provide training and care here. It became an exceptional bundling of forces. Hendry, the local physiotherapist from Haydom inspires and organises the whole event. He knows all the children and parents by name. He knows their history and their needs. The parents attended lectures, training sessions and were divided into discussion groups. Shedrack provided advice on technical tools like braces, customised chairs and shoes. He performed accurate measurements for devices and noted it all down in his book. He also used some nice conversation techniques to get the parents actively involved in the discussions.

In the meantime, Theresa examined the children one by one. With the ultrasound she investigated the kidneys where necessary, while showing the local doctor how to do this. Most children are doing well. One child had to be circumcised because the catheterisation was failing. A 16-year-old boy was dizzy without

identifiable reasons. Dr. Catherine from Moshi performed four operations on the second day. Here, one strikes when the iron is hot, as these poverty-stricken parents can't travel all the way to Arusha. What can be done now is scheduled and carried out immediately. Theresa has become a real tropical doctor who, when it is a matter of life and death, even performs neurosurgical interventions herself. During her two years in Haydom, Dr. Catherine taught her how to place shunts as there was nobody else who could or wanted to do it. Theresa also performs ultrasounds on a small machine that she brought from Germany and which she donated to the hospital. She has printed all our protocols and documents and made herself familiar with the continence management programme.

This initiative from Teresa comes as an unexpected gift from God in our fight for our children.

Theresa is enthusiastic and intelligent, modest but thorough. She listens and believes in the potential of children and their parents. She has enough doubts to not be too certain as this can be dangerous when you practice medicine. It is an enthusiastic bunch and we enjoy it quietly as we, IF and Child-Help, planted a seed for this a long time ago. Together with Child-Help, CCBRT and ALMC started programmes for spina bifida and hydrocephalus. They also enabled the amazing work of Theresa in Haydom. Through our project in Arusha they received shunts and the necessary incontinence material. It felt like one of the many missing pieces of the puzzle which finally came together. **And this puzzle**





in Haydom fits!

The parent group ASBAHT also sent Hidaya and Kilumba, two faithful staff members who have been around from the very beginning. They started the new ASBAHT department in Haydom and organised elections for a local leader. They spoke to the sometimes startled parents with great enthusiasm.

Theresa connects people in an enthusiastic way. She has done it here for two years and that's probably how this work started. She leaves behind a wonderful but fragile project. It is not a baby anymore, but a child that is growing up, that thinks it can handle everything but is still a bit dependent. Child-Help decided to continue supporting the Haydom team.

The new director of Haydom is from Tanzania. He agreed to a local network meeting at which we were all present: the Haydom team, the Arusha team, CCBRT, ASBATH, Theresa and Child-Help.

On the last day of our visit the director spoke to the parents in a very warm and human manner. He mentioned all the action points that were decided upon in our meeting. This provides hope, as in this way he shows that the management embraces the project warmly. **We are happy with this puzzle where the pieces come together nicely.**

Pierre Mertens & Lieven Bauwens

Pictures: Chelsea Bulteel

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