



CHILD-HELP

FOR CHILDREN
WITH AN IMPAIRMENT

A FAIR START

WWW.CHILD-HELP.BE

“A FAIR START”

A PROGRAMME BY CHILD-HELP

Even in Belgium, being born with an impairment is often a difficult start of life.

In developing countries chances to be born with an impairment are a lot bigger than over here. These children have bad luck twice: in the country where they are born, healthcare is hard to access and on top of this an impairment enlarges the risk to poverty. Poverty is the direct cause for more children being born with spina bifida (open back) and hydrocephalus (water on

the brain) in developing countries. Without help these children and their mothers are outcast from society and those children - because they don't get the necessary care - develop extra impairments that are preventable.

Child-Help wants to improve the quality of life of these children with the programme ‘a fair start’ by timely detection and lifelong care.



Ambrose works for Child-Help in Western-Uganda. He makes home visits and trains parents in necessary care.

WHAT ARE SPINA BIFIDA AND HYDROCEPHALUS?

Spina bifida literally means ‘split spine’ and is a **birth defect**. Very early in the pregnancy the spinal column doesn't close completely on one or more places. The nerves are interrupted or don't develop well, with **paralyses** as a result.

At birth the baby has an open wound on the back. The paralyses cause most of the time **incontinence** and when not treated properly harm to bladder and kidneys may occur. 66% of people with spina bifida have a disturbed balance between production and absorption of the water in the brain. This results in a progressive hydrocephalus.

Hydrocephalus also occurs apart from spina bifida, as a result of obstructions caused by bleeding on the brain, infections or tumours.

It is crucial to **intervene quickly and efficiently** from birth. The back has to be closed surgically to prevent infections. If the head grows too fast, the excess of brain fluid has to be corrected surgically otherwise the risk for brain damage is big. With a silicon tube (also called shunt or drain) one drains the excess of brain fluid. With an endoscopic procedure one can nowadays create a natural bypass. Complications, especially infections, are seen more with shunts than with the endoscopic procedure and especially in developing countries this is a big important progress.

CHILD-HELP

FOR CHILDREN WITH AN IMPAIRMENT

Child-help started from the solidarity between people confronted with spina bifida in Belgium and their companions in the South. They feel involved because they know how complex it is to take care of a child with a birth defect and to **guide it to a full and independent life**.

Child-Help is an active part of the IF-platform for international solidarity within the bosom of IF, the world organisation for Spina Bifida and Hydrocephalus (www.ifglobal.org).

IF has the consultative status with the United Nations and works together with WHO, Unicef, FFI (flour fortification initiative) and many other associations. In Belgium Child-Help is a member of PHOS (platform for handicap and developing cooperation).

WHAT DOES CHILD-HELP DO?

Child-Help especially makes an effort for children with spina bifida and hydrocephalus in developing countries. Shortly after birth this means surgery. The back has to be closed surgically and if the baby develops hydrocephalus, it needs a shunt to drain the excess brain fluid. To guarantee quality of care, **training and quality control** of all persons involved is needed: children, parents, self-help organisations, nurses, paediatricians, paramedics and surgeons.

Where necessary, Child-Help gives the missing **medical materials** and in all the projects, it supports the **parent groups**.

Child-Help expands with **local partners** a programme that assists these children and their parents for the rest of their lives.

THE DISEASE OF THE POOR

By primary **prevention with folic acid** but most of all by **prenatal screening** followed mostly by termination of the pregnancy, it is sporadic nowadays for children with spina bifida to be born in Belgium. So spina bifida becomes more and more a handicap of the South **where adequate care doesn't exist**. We estimate the incidence in developing countries to be around 3/1000 live born babies. In some areas up to 1/150! This makes the work of Child-Help so relevant. We offer these children, belonging to the poorest of the poor, a fairer start.

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Hydrocephalus also occurs more in the South. 3 out of 4 of the children we help in Africa were born normal. Probably by **unfavourable circumstances at birth** babies get infections that via meningitis lead

to hydrocephalus. Also malnutrition of the mother is causing premature births. These premature babies have a higher risk for bleeds on the brain, which can cause hydrocephalus. **Poverty is a direct cause for these handicaps.**

In rural areas one knows about spina bifida and hydrocephalus but not about existing treatment. Young parents first go to their local healers who still think spina bifida and hydrocephalus are incompatible with life. They often blame the parents by saying they are bewitched and perform exorcization rituals using sometimes red-hot iron sticks to burn the head of the child as form of 'treatment'. On top of these horrible burn wounds these practices cause a loss of valuable time that causes extra handicaps for many of these children like for instance a head that becomes too big, more severe paralyses and blindness.



He listens to the children, examines them, supports the parents and involves the neighbourhood in the care of this special child.

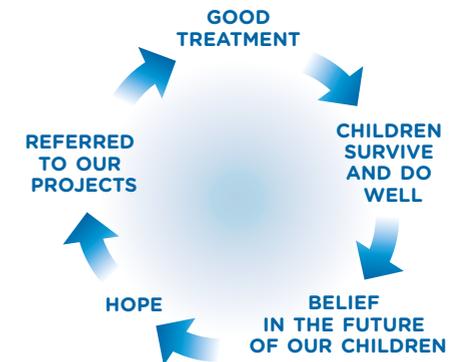
More and more parents find the way to our partners for **care, follow-up and support**. Luckily we see less children arriving too late for treatment.

In the projects of Child-Help children get the needed treatment. This way Child-Help breaks through the negative circle without hope to a **positive circle of hope where treatment leads to a better future**. Only if people see a positive future for their children with spina bifida and hydrocephalus, they will refer them in time for treatment.



In many developing countries one doesn't believe in a future for children with hydrocephalus.

A negative circle starts that keeps on being confirmed. No treatment leads to children in helpless situations. This negative image of the handicap causes people not to believe in their future and so the children are not referred for treatment.



If these children get treated in time, they can expand a full life in the family, neighbourhood and mainstream school.

HOW CHILD-HELP DEALS WITH THIS

Child-Help only works with **local organisations and hospitals** adding to what exists and is available to care for 'our' children. This means our commitment and strategy is adapted to the local needs. Quality norms and approach are the same everywhere.

Uganda for instance

In Uganda we work with the **CURE hospital** in Mbale. This hospital was opened in 2000. Co-workers of IF were there from the start of this beautiful project and found funding that made endoscopic surgery possible. Each year they operate on more than 1000 children.

Our hospital in Mbale now trains surgeons from the whole world in endoscopic surgery which makes shunting superfluous for 70 % of the children. This is an enormous and very real improvement in the life quality of our children.

The hospital does the follow-up in four locations, spread over the country.

When they celebrated their tenth anniversary, their director, Derek Johnson, said: *"Since we opened our doors, we've already seen more than 35000 children and performed 7500 neurosurgical operations. We transformed many children's lives and gave thousands of families new hope."*

Also children who were treated too late get care at home, Ambrose shows the mother how to support the child's head.



Endoscopic surgery is an important break through in the improvement of the quality of life for children with hydrocephalus.



At this occasion, Child-Help offered a cheque for € 60000 to invest in the training of surgeons from many other countries. This way Child-Help contributed to the **training of surgeons** from Tanzania, Vietnam, Nigeria and Bangladesh.

Because timely intervention prevents additional handicaps we offer campaigns in Uganda through **radio, TV, brochures and posters** to ask attention for **prevention and treatment of spina bifida and hydrocephalus**. Brochures were translated into English and the mayor local languages as Luanda, Rynyankole and Luau and distributed in 11000 copies. 2000 posters were distributed all over the country in local health centres and hospitals.

Because children from all over the country come to our hospital, the follow-up is done regionally. The hospital does the follow-up in four locations, spread over the country.

This happens in cooperation with community based rehabilitation (CBR) projects that organise these clinics. CBR is also promoted by WHO.

In Uganda we work together with CBR projects in Kampala (Katalemwa Cheshire Homes), in Mbarara (OURS), in Gulu (AVSI) and with several regional parent groups. They make house visits and besides medical follow-up they also provide for other important aspects, like: **integration in the community, schooling, mobility and tools**.

CARE FOR CONTINENCE

90% of people with spina bifida are incontinent as a result of paralysis.

This leads to a very high risk for infections and damage to the bladder. On top of this not being dry is socially very disturbing. Therefore professionals of the university hospital in Leuven developed together with our local partners a successful continence programme that keeps the children dry and clean for urine as well as for stool. **Using the right material, medicine and a few simple techniques we train parents and children.** After a few days we already see some result and the children are dry and clean. This prevents pressure wounds and damage to the bladder and allows children to go to school and become full members of society.

Nearly all children with spina bifida are born with a normal bladder and intact kidneys. The bladder is intact but paralysed. Due to this paralysis damage to the kidneys can develop quickly. Therefore it is important at birth to find out diagnostically which type of paralysis it is.

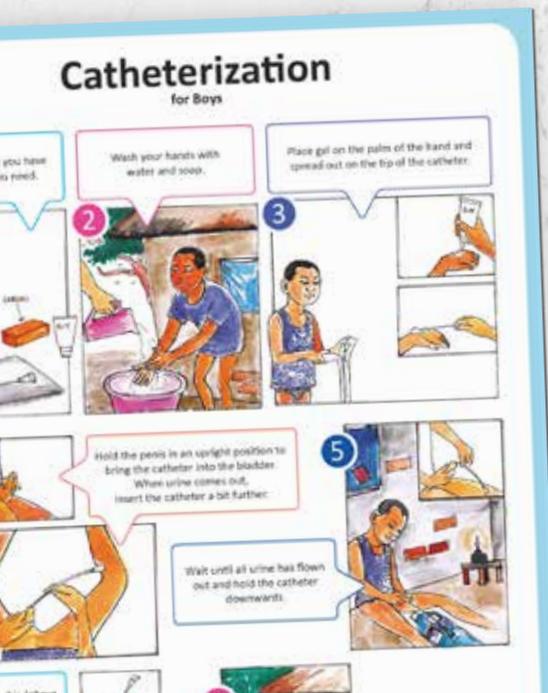
In Belgium the diagnosis is made using complex and costly urodynamic tests. In our projects we have equally good results with simple tools like measuring the volume of the bladder and the pressure inside it. This we do using a tape measurer, a little tube and a well trained nurse.

The parents get information of her and are trained to do this at home too. Some children learn to do the procedure themselves from the age of 4 - 5.

We developed **posters** explaining step by step the procedure.

As for the stool incontinence we teach the parents to keep their children stool free for two days by bowel wash outs. The children learn how to do this themselves as soon as possible. The CBR worker pays extra attention to the home situation. Often it has to be adapted in order for the care to be done independently. Also at school or in the work environment there might be the need for an adapted room to make the procedure possible.

Together with the parents we developed a **brochure for teachers** asking attention to the special needs of children with spina bifida and hydrocephalus.



SHIP THE SPINA BIFIDA AND HYDROCEPHALUS INTERDISCIPLINARY PROGRAMME

Living with spina bifida and hydrocephalus is about more than surgery.

This care has to be interdisciplinary and with the disabled child in the centre.

Our programme has attention for all aspects of life with a handicap. **Surgery opens the door to a full and respectful life but behind that door there is a house with many rooms of needed care.**

Care shouldn't focus only on the specific medical needs connected with the handicap but also on the general health of the child and the parent(s) : Hiv, malaria, inclusion, education and employment.

For lifelong care we developed the SHIP concept. SHIP stands for **Spina bifida & Hydrocephalus Interdisciplinary Programme**. SHIP emphasises a coordinated approach between the different partners in care: the neurosurgical hospital, the CBR centre, ambulant clinics, parent groups and several authorities...

Mother and child already had to overcome many obstacles before reaching the hospital. Together with experienced parents we listed all these obstacles and looked for suitable solutions. Many children are paralysed and have mobility issues and are incontinent. This hinders integration in the society and also the schooling and later there are often problems with the employment that need attention.



Our hospital in Mbale: parents and children have often travelled far before they found the care they have the right to.



Ship is about all aspects of a full and inclusive life for which parents and parent groups are crucial and central.

In Belgium university centres developed **multidisciplinary care** where several medical and paramedical disciplines work together to organise the care as well as possible. They have the different specialisms under one roof and one management. In developing countries many partners have to work together from large distances.

SHIP facilitates the cooperation between all caregivers. Parents and parent groups are the centre. SHIP wants to strengthen the parents in their important task. Therefore parents - next to all professional workers - are privileged partners in care. They are coached to raise their children into articulate and independent adults.

Youngsters and adults with spina bifida and hydrocephalus are actively involved in the parental working and are important role models for the younger children. Apart from this they have their own group.

To improve the communication between the professional workers we developed a **SHIP passport** in which all important facts of the child are noted and the different interventions registered. This passport remains with the parents and later with the child.

EDUCATION TOWARDS ADULTHOOD

Child-Help assists parents in educating their children towards adulthood.

A kid will learn to swim when it can overcome his fear for water. The parent's role is to ensure that all steps towards adulthood are safe enough so that the child can cope with them without anxiety and building up self-confidence. Parents have to find the

right balance between presence and letting go. This starts early in life. Adulthood does not mean being independent of care from others. It means being able to organize as much as possible the care you need. Child-Help uses a developmental approach outlined in a tool called **"Growing up Ready"** that highlights the skills needed by children and parents to find the right balance between being present and letting go.



PROGRAM OF YOUNGSTERS AND ADULTS WITH SPINA BIFIDA

Youngsters and adults with Spina Bifida and Hydrocephalus have specific problems they do not always want to discuss with their parents. They learn the most from their peers. That's why Child-Help supports their **self-support groups**. It enables them to build up self confidence and being responsible for the care that they need. Youngsters and adults have a lot to discuss, like: the care of their changing body, their impairments, their moods, find-

ing meaningful occupation/leisure/employment, coping with in- or exclusion, being as much as possible independent from the care of others, relationships, sexuality, ... They want to meet without the parents. Nevertheless many of them remain active in the parent organizations. Child-Help is proud to employ some of them as staff in its programs.

Training is given and protocols discussed and tried out in the yearly workshops. SHIP was developed with these people.



TRAINING AND NETWORKING

The care for our children is complex and therefore permanent quality control and adjustments are needed.

That's why Child-Help works together with other organisations within the IF platform for international solidarity. Here **expertise is shared and developed**. All partners within the platform use the same quality norms and protocols for the treatment of spina bifida and hydrocephalus and for the follow up of children and youngsters with spina bifida and hydrocephalus.

Every year this platform organises a **workshop** that gathers the local partners around a current theme in care. Themes like neurosurgery, continence management, inclusive education, parent groups and interdisciplinary care are dealt with.

These workshops are inspiring for our partners, they give feedback and can adjust our policy where needed.

Involving the parents is the best guarantee for realistic assistance.

In all workshops, also if they are on medical disciplines, we involve the parent groups. They guarantee realistic assistance the best. Each workshop is a meeting point for parents and professionals from the South with colleagues from the North.

A FAIR START, A HUMAN RIGHT

International treaties such as the *Rights of the Child*, the *Convention for the Rights of people with a handicap* of the UN and the *Resolution on Birth Defects* of the WHO underline that children with a birth defect, also in developing countries, have a **right to a fair start**. Most countries signed these conventions but in situ little or nothing is visible; They have other priorities. Most of these children and their parents are left to their lot.

Because the people of Child-Help know what it is to get a child with a birth defect they want to do something to help. In view of the conventions they translate their knowledge and experience with the treatment of those children and their families into **actual and feasible actions in the South**.

These projects help the poorest of the poor in this world. They are –excepted for their parents- invisible and so no priority. For Child-Help children with spina bifida and hydrocephalus and their parents come first. They are our target group and our most important partners. Because **integration starts within the family!** In all projects parents and their organisations take an important place and responsibility. **It's all about them.**

The photo's in this brochure are taken by Io Cooman who has followed the CBR project of Ambrose in Mbarare for a few months. This exhibition was shown in HETPALEIS in Antwerpen and in the central hall of the WHO in Geneva.

Through house visits our rehabilitation worker can help to size the needs and possibilities of the child with spina bifida.



OTHER PROJECTS

Child-Help also has projects in Tanzania, Kenya, Peru, China and Congo.

In **Tanzania** we work with the ALMC hospital where we've employed an Italian paediatric surgeon for two years. She was trained in our Kenyan project. Now she was relieved by a Tanzanian paediatric surgeon.

In **Kenya** Child-Help works with the hospital in Kijabe and is building a 'guesthouse' to accommodate parents and children before and after the treatment and train them.

In **Peru** Child-Help has a continence management programme in the Paz-Hollandesa hospital in Arequipa.

In **China** and in **Congo** Child-Help has a continence management project and provides surgeons with shunts.

South-Africa is becoming more important for Child-Help for training and quality control of our projects because for years already they've provided a well balanced care for spina bifida and hydrocephalus.

Child-Help also accepts the demand for medical material –mostly shunts- in many other developing countries.

Child-Help also helps preventing spina bifida by food fortification and supplementing folic acid and supports partners in the South to cater for adequate care for these children.

For figures we refer to our annual reports on our website www.childhelp.be

WHAT DO WE DO IN BELGIUM?

Child-Help wants to point out the **needs of the partners in the South** to people here with a handicap in general and especially with spina bifida and hydrocephalus and their caregivers. That's why we work together with the Flemish and Walloon associations for spina bifida and with other organisations like PHOS, Handicap International and Light of the World.

Child-Help also wants the Belgian development cooperation to pay more attention to people with a handicap in the South.

Child-Help organised **awareness campaigns** in Flanders and Wallonia to improve the solidarity with people with a handicap in the South and to raise funds for her **projects in the South**.

Child-Help has an informative stall on World parties, information days, gives **lectures** on demand and organises **activities** like theatre plays and exhibitions.



Child-Help is solidarity with and by people with spina bifida and works closely together with VSH, the Flemish association for SB & H.

HOW CAN YOU HELP?

Child-help depends on donations. You can support us by a donation on **738-0197170-88**, donations from € 40 are tax deductible.

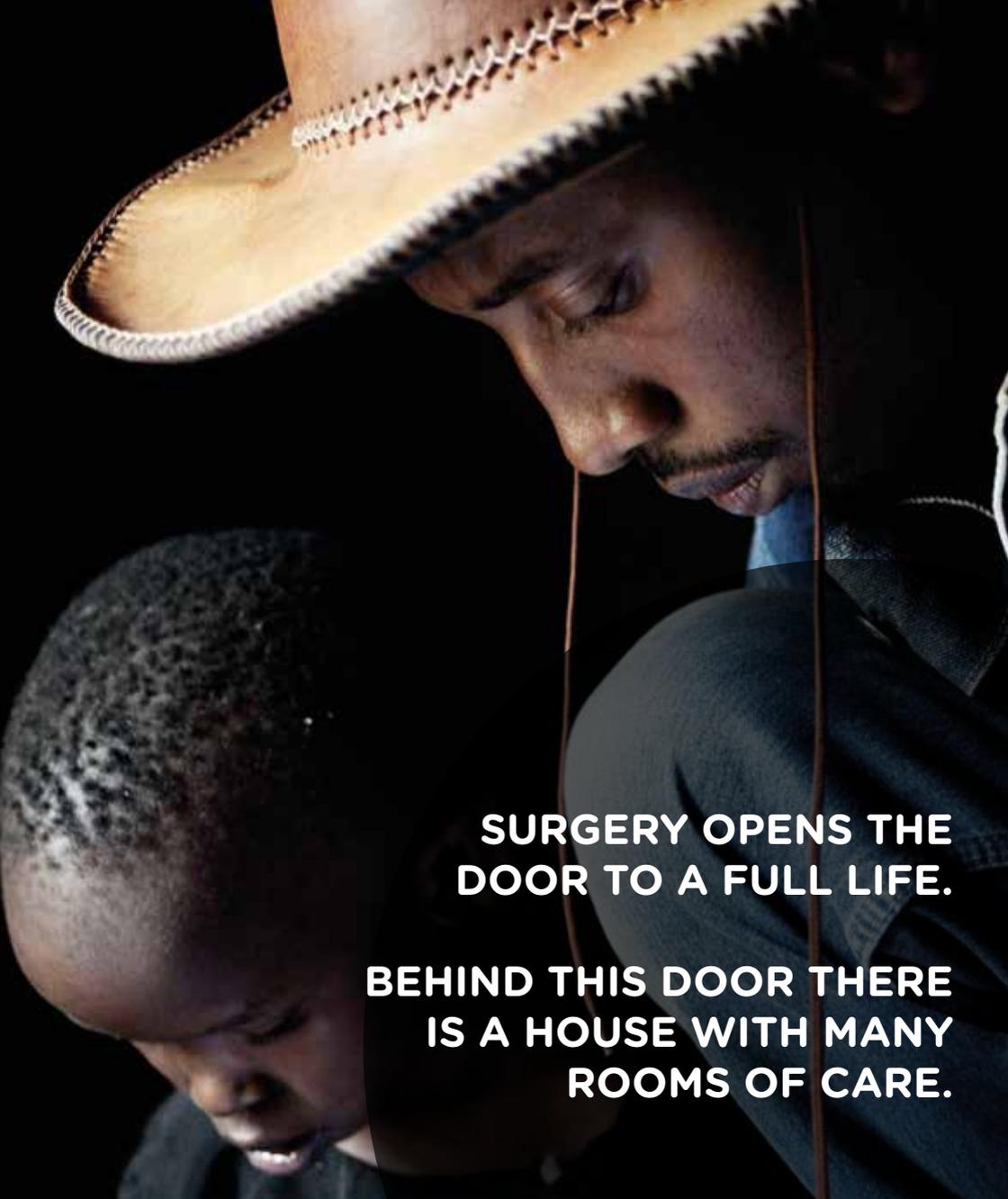
Contact Child-Help to develop an action in aid of children with spina bifida and hydrocephalus in developing countries.

This work is only possible by the commitment of many **volunteers and donors**. Your commitment as a volunteer is more than welcome.

Support Child-Help and give children with a birth defect in developing countries a fair start!



In order for children to become part again in the community they were born, Ambrose involves neighbours for the rehabilitation.



**SURGERY OPENS THE
DOOR TO A FULL LIFE.**

**BEHIND THIS DOOR THERE
IS A HOUSE WITH MANY
ROOMS OF CARE.**

Cellebroersstraat 16 – 1000 Brussels - account number 738-0197170-88

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