



MISSION AND VISION

Our vision is that by 2050 all children with spina bifida and hydrocephalus have a fair start in the world.

'Fair' in our vision means: fair with the cultural and economic context of the country.

Fair means also non-discrimination in the context of Universal Human Rights.

Fair means non-discrimination based on disability.

Our mission is to enable a generation where children with spina bifida and hydrocephalus become thriving adults in an inclusive society by working with parties worldwide.

INTRODUCTION

TOWARDS POSITIVE CHANGE

War elevates the risk for young women to give birth to babies with spina bifida. In war zones, access to care and timely treatment is virtually non-existent for children with disabilities. The vast majority of children with spina bifida & hydrocephalus today are born in the Global South, where access to timely care remains severely limited. According to our estimates, this affects more than one million babies a year worldwide. This is a global health issue overshadowed by the day's news and constantly under-reported.



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parents do not
wait passively.
They undertake the
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Adopting 'Positive Change' as the central theme of this annual report is not a cynical intention. It is not a hopeless cry in the wilderness; rather, it signifies the opposite.

Philosophers such as Nietzsche, Sartre, and Camus argued that hope can lead to passivity, where injustice is merely endured without action. They advocate for a life in which people take full responsibility and seize control of their destinies instead of placing their fate in the hands of hope. But can we reasonably expect this from innocent war victims or a dying child on a waiting list for a life-saving operation?

Their determination, courage and joy in the face of immense challenges are truly inspiring. - Daniil

Just as those philosophers urged for action, Child-Help echoes their call in this annual report. When you commit yourself to take action in pursuit of change, you transform that hope into faith.

In our project countries, most parents do not wait passively. They undertake the long journey to the hospitals we partner with. On reaching one of our 15 Houses of Hope, they meet adults with spina bifida, like Beautiful, whom we feature in this report. Her story is one of alternating difficult and good periods and a powerful resistance as she advocates for positive change in her country, Uganda.

Initially supported by her brothers, sisters and parents, who have continued to fight for her, Beautiful also found support from older peers and Child-Help staff. Her father learned from the experiences of other parents. He became actively involved in SHAU (Spina Bifida and Hydrocephalus Association of Uganda), the Ugandan support group supported by Child-Help since its inception. SHAU gives a voice to the needs of its members and fights for an inclusive society in Uganda. Child-Help builds on the love of these parents for their children.

Love is what remains when all else is lost; as a poignant melody echoes from the radio.

In South Africa, the Zulu expression "Umuntu ngumuntu ngabantu", meaning "I am because we are", embodies the unity among people facing shared challenges.

It underpins the effectiveness of our self-help groups. Together with them, Child-Help calls for action.

The past year has presented challenges for Child-Help. Several of our donors were impacted by the energy crisis resulting from the Russia-Ukraine war. It is often said that when you are hungry, you are more likely to get a piece of bread from someone who is also hungry. Therefore, even during this financially challenging period, Child-Help and its donors demonstrated solidarity with the victims in Ukraine and Gaza.

Reduced revenues prompt us to communicate better about our work and to allocate our resources more efficiently. We seek to grow our partnership network with other organisations that believe in our story and share our vision.

Because we have a good story. We are building on a growing community of adults with spina bifida & hydrocephalus whose survival is attributed to our efforts. Many of them, like Beautiful, are our ambassadors. Several others are now employed within our projects, giving hope to young parents. There is also encouraging news: spina bifida & hydrocephalus are more easily treatable these days. Child-Help has developed effective methods for optimum care, even in low-income countries.



With medical advances, the prospects for children with spina bifida have never been brighter. Through primary prevention and ongoing research, the incidence of spina bifida can potentially be reduced by up to 70%.

In 2023, Child-Help critically reviewed its 30 years of engagement in the Global South. Now, we are building a long-term vision for positive change with all our partners. Our ambitions are far from modest: a world where children with spina bifida & hydrocephalus become driven adults in an inclusive society. Moreover, by 2050, every affected child should receive a fair start in life in their country, regardless of their place of birth.

Nietzsche is right; passive hope will not get us there. Cooperation will.

Our projects in the Global South are designed to make a tangible difference. Child-Help was founded by people with the disabilities it represents. Our primary partners are, therefore, the parents, children and adults with spina bifida & hydrocephalus, along with their representative organisations. To highlight this commitment, our last annual report centred on the themes of decolonisation and equal partnership.

Continuing this spirit, Child-Help is now seeking to expand collective action further with local and international initiatives of surgeons, researchers, rehabilitation workers, donors, foundations and policy makers. With one million new cases a year, it's clear we cannot tackle this alone.

Only together can we secure the resources needed to give every child a fair start in life. I am convinced that ample resources exist to support impactful projects like ours.

With everyone believing in our mission, Child-Help will achieve even more positive change in 2024.

Join us on this road to positive change!

Pierre Mertens Chairman CHI



Everyone is equal here. - Daniil



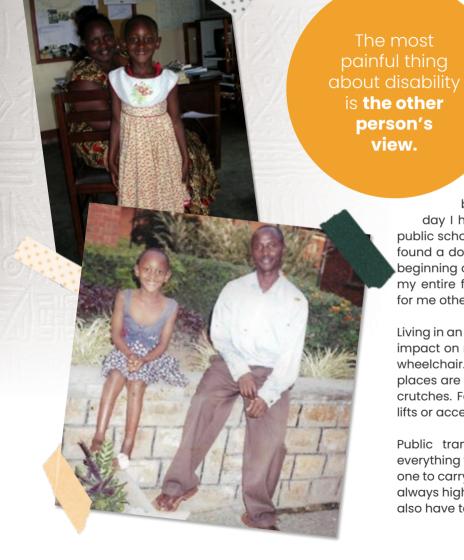
The nearby health centre couldn't help us and sent us to Kisiizi Hospital, a five-hour drive away. Transport cost a lot of money, and medical care had to be paid for as well. My parents searched for alternative options, but real help came late. With my medication and transport fares costing so much money, my parents could no longer pay my siblings' school fees. As a result, they were expelled from school.

The lack of proper treatment for clubfoot and limited knowledge of Clean Intermittent Catheterisation led to a lot of complications for me. It meant I ended up having many surgeries that could have been avoided. With a clubfoot, timely cast treatment and physiotherapy can often avoid surgery. Unfortunately, my parents had little knowledge about it.

During that same time, IF-Child-Help was developing vital care programmes with Cure Children's Hospital of Uganda in the eastern part of the country. They were also working on a community-based rehabilitation (CBR) project in the capital, Kampala, with Katalemwa Cheshire Home. But here, in the west, a collaboration between Child-Help and OURS (an organisation for people with disabilities) on a similar CBR project had yet to get off the ground. This eventually happened under OURS' new director, Kordelia Fisher, who had previously worked with IF-Child-Help in Lusaka, Zambia.

With Child-Help's support, Kordelia teamed up with CBR worker Mr. Gashanga Ambrose to start a project for spina bifida & hydrocephalus. Thanks to them, I was referred to Cure Hospital in Mbale for surgery, where I finally got the proper treatment. But, Mbale is located in the Eastern region, while I'm from the Western region – this meant more lengthy journeys and high travel costs that weren't easy to afford.





Ambrose became a real mentor to me and my whole family. He came to our home and taught us all about my disability.

As a child with spina bifida, I couldn't control my urine and stool due to bladder and bowel incontinence. This led to a lack of self-acceptance and rejection. For example, I wasn't accepted at the nearby public school because of my condition. Every day I had to walk more than 5 km to get to another public school, just like anyone else. Fortunately, Child-Help found a donor willing to pay my school fees. This was the beginning of hope and light, not only in my life but also for my entire family. Education wouldn't have been possible for me otherwise.

Living in an unsuitable environment has had a big negative impact on my life. Now, I can walk, but I was regularly in a wheelchair. Schools, hospitals, banks and other important places are inaccessible to someone using a wheelchair or crutches. For example, most buildings don't have ramps, lifts or accessible toilets.

Public transport isn't adapted; you have to arrange everything yourself. I always had to make sure I had someone to carry me on and off the bus. And transport costs are always higher for someone with a wheelchair because you also have to pay for your wheelchair.



These are all practical things that make life difficult. But, the most painful thing about disability is the other person's view. Many people only see the disability, not who you are and what your abilities are. I have a disability, but I'm much more than that alone. In Uganda, disability is still often seen as a burden on the community.

We have little or no access to what we should be entitled to. We want to be able to make our own choices. Access to appropriate treatment is a big issue. Training and employment are, too. Employers aren't always willing to hire people with disabilities, even if they have all the qualifications for the job.

The effects of spina bifida hit some harder than others. For instance, I didn't develop hydrocephalus. The disability can be different for everyone, but even a mild form can still really affect your life. Some years I lived very independently, while others I was in a wheelchair or walked with crutches. I've had 21 surgeries in my life. In one particular year, I had as many as seven operations. That made me depressed and insecure. I missed many months of school, which greatly affected my performance in class. This especially hurt because when you're always in hospital, you can't enjoy life like other teenagers your age.

Medical care for individuals affected by spina bifida remains challenging, even for minor issues. In my experience, medical staff often referred me back to the hospital where my first operation took place, labelling me as a special case. Routine medical referrals directed me to Mbale for treatments of common diseases that could easily have been handled locally.

The cost of the appliances I needed added to the frustration; they were very expensive, and we couldn't afford them. This kind of financial barrier often gets in the way of rehabilitation efforts. Fortunately, Child-Help provides incontinence materials and medication. To keep it affordable, we reuse the catheters. When there are none, it's a disaster!

My biggest support always comes from my brothers, sisters and parents, especially my father, who loves me so much and supports my mother in raising me. He's been active for over five years in the local chapter of the Spina Bifida & Hydrocephalus Association Uganda (SHAU), the support group that IF-Child-Help helped found.

This is how I came to

believe in myself

and my future.

My dad believed in me and supported me in everything. This is how I came to believe in myself and my future. It's extraordinary that a father in Uganda believes in his disabled daughter. Many men see a child with a disability as a curse and blame the mother for it. They often leave the family or disown the mother and child from their family.

Ambrose helped me in many aspects of my life and rehabilitation. He came to my home and involved my community in my care. He made them aware of what my disability was and what my rights were. This contributed to the community's positive attitude towards me. He was both my mentor and source of inspiration. He was my SHIP coordinator and empowered me to stand up for myself. (SHIP is the Spina Bifida & Hydrocephalus Interdisciplinary Programme that Child-Help has implemented all over Africa.)

I learned step-by-step from Ambrose how to live an independent life. This taught me how to take care of myself, especially to deal with my incontinence. I was soon clean and dry. That's how joy came back into my life and how I became the warrior I am today. Through joining youth groups at SHAU, where I served as a National Youth Leader, I learned a lot, especially from older children living with spina bifida. Child-Help has helped and supported these groups from the start. By sharing experiences, I have come to realise that I am not alone, which provides tremendous support. Seeing how others are successfully managing their lives is truly inspiring.

I now also want to be a support to others. I have learned to love myself as I am and have seen how important it is to be positive in life. I want to share that with young mothers so they can believe in the future of their special babies. I encourage young mothers not to lose hope because we're living examples of what tomorrow can bring.

But there's still a lot of work to do. Together with SHAU, we need to sensitise schools and hospitals and teach them how to treat people with disabilities. It's also important to educate women and young girls about folic acid to prevent spina bifida. I want to be a voice for the voiceless and offer a shoulder to lean on. We can handle a lot, but we also need lifelong care and support. You and I can make that happen. Together, we are stronger!

It feels like a privilege and a dream come true for me to share my story with Child-Help. I hope my testimony will help anyone who has been rejected or abused because of their disability. To me, you are only truly strong when you find the strength to persevere despite the many obstacles that come your way. When you can do that with a disability like mine, then to me, you are a real hero.

Just because others only see your disability at first doesn't mean you are that disability. I learned that I am much more than my disability alone. Everything depends on how you deal with it. It's not our disabilities that count but our abilities."

I want to be a voice for the voiceless and offer a shoulder to lean on.



ACCESS TO SURGERY

Surgery opens the door to survival for individuals with spina bifida & hydrocephalus.

But, beyond that door, an entire spectrum of care is essential to lead a full life – what Beautiful conveys so clearly.

Child-Help has made significant investments in surgery, with Uganda playing a pivotal role in revolutionising global care. When Dr Ben Warf established the Cure Hospital in Mbale, Uganda, Child-Help was already by his side. Leveraging resources from Norway, Child-Help donated all necessary materials, helping Dr Warf to innovate in treating hydrocephalus using a flexible endoscope in Africa. Dr. Warf has shared these novel techniques and knowledge with neurosurgeons worldwide. From its partnership with Cure to its latest collaboration with NeuroKids, Child-Help continues to train neurosurgeons all over the Global South, including providing them with the right equipment.

Child-Help has made significant investments in **surgery.**

Child-Help encouraged Dr Warf and his team to test a low-cost Indian shunt. They conducted a comparative study, contrasting this affordable option with pricier alternatives from the Global North. Their findings, published in a peer-reviewed journal of paediatric neurosurgery, showed they work equally well. This outcome fuelled Child-Help's motivation to donate thousands of shunts every year to parents who might otherwise struggle to afford them.

Surgery opens the door to survival for individuals with spina bifida & hydrocephalus. - Pierre

WHO IS WHO AT CHILD-HELP INTERNATIONAL

I AM BECAUSE WE ARE CHILD-HELP IS ABOUT MANY PEOPLE. HERE WE HIGHLIGHT SOME OF THEM.

CHILD-HELP INTERNATIONAL GOVERNING BOARD



PIERRE MERTENS PRESIDENT

"The fight for, and with children with disabilities confronts us with the most fundamental values in life" My first child was born with Spina Bifida and Hydrocephalus in 1978.

With my wife, Mol, we started the Belgian Association for Spina Bifida (1979). In 1995 I was elected as president of the International Federation for Spina Bifida and Hydrocephalus (till 2013). During my presidency in the nineties, I started projects in the Global South.

I was also a board member of European Disability Forum (EDF) till 2012 and I am a member of the board of the Bo Hjelt research foundation and president of Child-Help International.



LIEVEN BAUWENS

"From primary preventative measures to care for persons with Spina Bifida and Hydrocephalus, the response should always be multidisciplinary"

I was born in 1977, and I have a brother with Spina Bifida and Hydrocephalus and I've been active in the SBH movement for years, as former Secretary General of the International Federation for Spina Bifida and Hydrocephalus (2005-2019), briefly serving as its president.

I worked as managing director for Child-Help International from 2019 to 2023. During my work, I focused a lot on prevention and food fortification.



PATRICK DEVLIEGER

"Disability provides us with a lens on culture and society"

I was first introduced to children with disabilities and their parents when I worked as a Belgian NGO-volunteer with my wife Martine in a center for children with physical disabilities in DR Congo from 1983 to 1985. I continued to work as an anthropologist and an educator with an interest in disability and culture in the Global South, in collaboration with the United Nations, non-governmental organizations, and universities.

I am a co-founder of Child-Help and work as a board member for Child-Help International and staff member of Child-Help Belgium.



RUTH NALUGYA

"In the quiet strength of caregiving, wisdom blooms."

I am a dedicated mother advocating for individuals with spina bifida and hydrocephalus, currently serving as the Executive Director of the National Umbrella Organization for Spina Bifida and Hydrocephalus Association (SHAU).

My commitment extends beyond administrative roles; I actively participate in various government technical working committees related to disability, rehabilitation, education, and social development. Additionally, I am a social scientist, contributing significantly to research in my field. I am dedicated to being a true force for positive change.



CHARLES HOWARD

"When I approach a child, s/he inspires in me two sentiments: tenderness for what s/he is and respect for what s/he may become."

— Louis Pasteur

Born in a mission hospital in Eswatini, my family and I are now based in Kijabe, Kenya. I have spent over 25 years living and working in Africa. My professional experiences include global business, clinical social work, university teaching, global health administration and program development. In working with Neurokids over the past 10 years I have cultivated and developed partnerships at over 60 hospitals in 25 countries in the Global South related to hydrocephalus and spina bifida.

CHILD-HELP INTERNATIONAL STAFF



JANET MANONI
DIRECTOR OF PROGRAMMES

I believe in building people to become leaders and the Spirit of UBUNTU - I am because we are. After a tragedy where I lost my family from cancer, I made a decision to dedicate my life to serving humanity. It's been 10 years now in this fulfilling journey.

I am a Mandela Washington Fellow - YALI (Young African Leaders Initiative). Waldorf Early Childhood and Special Needs Specialist.

SOLOMON BAGANJA DIRECTOR OF FINANCE



A few years ago, during an assignment with CHI, I encountered a condition that had remained largely unknown to me until then: Spina Bifida and Hydrocephalus (SBH).

This was despite growing up with a sibling that had the same condition. This lack of awareness struck me profoundly, highlighting the urgent need for education and advocacy surrounding SBH.

As the Finance Director at CHI, I recognize the pivotal role systems and processes play in transforming organisational effectiveness and efficiencies.

Our work therefore extends beyond traditional Financial Management as it encompasses building the capacities of our representatives to be an active and alive voice for the target group.



HAKIM BAYAKUB
COUNTRY REPRESENTATIVE
AND EXECUTIVE DIRECTOR
CHILD-HELP TANZANIA

I was a father of a deceased daughter with hydrocephalus, and I am a former president of the parent association (Association for Spina Bifida and Hydrocephalus Tanzania - ASBAHT), which I served for 22 years, from 2000 to 2022.

JULIANA AUMA COUNTRY REPRESENTATIVE OF KENYA

I am a parent to a young adult born with Spina Bifida and Hydrocephalus and a passionate advocate of disability rights. As the founder of the Spina Bifida and Hydrocephalus Association of Kenya- SHAK I believe that the true meaning of life is to plant trees whose fruit you do not expect to eat.





COLLINS KABACHELOR COUNTRY REPRESENTATIVE OF UGANDA

I am passionate about children with SBH having served with both treatment and rehabilitation partners for the last 17 years. The results are evident when we are consistent in what we do. I currently oversee five implementing partners, ensuring the successful implementation of SBH programs across Uganda.



I am a husband and father of one kid (a boy called Joshua) and I like my job very much.





SIFA JOHN COMMUNICATIONS AND INFORMATION OFFICER

I am Sifa John, a mother, a friend, a servant.

As long as I can make someone else's life okay, I am okay. My role is Communications and Information Officer.



HIDAYA ALAWI

I'm Hidaya, CHT's Continence Management coordinator, and I'm here to help our children with incontinence issues become confident and live normal lives.

As a mother of a teenager born with Spina Bifida I understand the importance of this training program to people with Spina Bifida and their families.

I'm dedicated to spreading my knowledge on the significance of Continence Management to the community.



MILICA MILENKOVIC ASSISTANT

Joining Child-Help International 4 years ago made my first connection to disability. Nevertheless, ever since I was a kid, I always wanted to help people, and prevent injustice. The way to do that is through fairness and doing the right thing.

People around us, especially the vulnerable groups, such as children with spina bifida and hydrocephalus, and their parents, need to know they have someone in their corner, fighting with and for them. That is how we get to a better world.

CHILD-HELP MEMBERS



MIEKE VAN POUCKE COORDINATOR AT CHILD-HELP BELGIUM

I'm passionate about contributing to a sustainable future for our planet and making sure that no one is left behind. What matters to me, is to take care of vulnerable people in our society, in my own village or on the other side of the world. I want them to be part of an inclusive society and make sure they believe in themselves. I started my career at the Red Cross, where I helped victims of wars and natural disasters.

Today, I'm very proud to be a member of the Child-Help family, who is fighting for a fair start for children with spina bifida & hydrocephalus all over the world.



LIES BLONDELLE FINANCE-ADMIN ASSISTANT CHILD-HELP BELGIUM

I got to know Child-Help in 2023 when my son Kaan organized a fundraising activity together with Child-Help to raise money for his native country Turkey, after the severe earthquake. When I heard a few months later that Child-Help was looking for a new employee, I didn't hesitate and immediately applied.

Being able to dedicate myself every day to children who need an extra support to be able to grow up confidently into driven adults gives me a lot of satisfaction.



JACQUELINE PIRKELBAUER, DIRECTOR AT CHILD-HELP GERMANY

With a deep love for children and a heartfelt commitment, I took over the management of Child-Help Germany in 2023. As a project management and marketing expert with half of my roots in Mexico and half in Austria, I worked in several countries in multinational companies.

Now I want to devote all my energy to helping children with spina bifida and hydrocephalus in the Global South. My goal is to make a sustainable contribution to improving their living conditions and to give them a fulfilling future. This decision is also based on my personal experience, as I grew up in a country where I saw poverty and know how much help is needed.



TANJA VRIELINK BOARD MEMBER AT CHILD-HELP NEDERLAND

Before I started working for Child-Help Netherlands in 2021 I was already working with local initiatives in Zimbabwe since 2008.

Having seen untreated children with Hydrocephalus with big heads living in pain (physically as well as mentally) and hidden from society, motivated me to raise awareness about the struggles of these children and their families.

In 2009 I read an article about a young man with Hydrocephalus from Senegal. He was fortunate to receive good treatment, attend school and study, being able to lead an independent life. His quote was "Bring Hydrocephalus out of the darkness". I've never forgotten about this. All children deserve and have the right to a fair start in life. Child-Help is an organisation to support that through networking worldwide, sharing knowledge and support with medical

DIRK DE WACHTER AMBASSADOR OF CHILD-HELP

equipment.

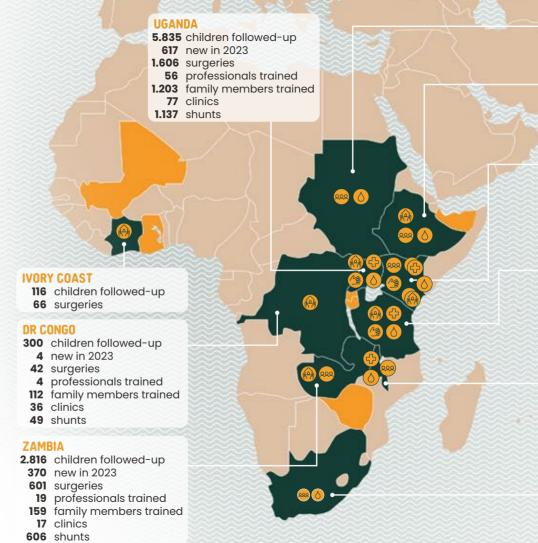
"Child-Help supports wonderful initiatives that have emerged from the bottom up, something we can learn a lot from in the health care sector"

Professor Doctor Dirk De Wachter is ambassador of Child-Help: He is a psychiatrist and known to the general public for his best-sellers 'Borderline Times' (2012) and 'The Art of being unhappy' (2019) and his numerous media appearances. His books have since been translated several times.

He holds a mirror up to society and brings a strong message of hope and acceptance of imperfection.



RESULTS 2023 Parent Group UKRAINE 708 children followed-up Members of Child-Help International Hospital project **47** new in 2023 38 surgeries Project countries 121 professionals trained Outreach project 77 family members trained Material support House of Hope Continence Mgmt 22.564 children followed-up worldwide **GUATEMALA** 139 children followed-up 21 new in 2023 63 surgeries 2 professionals trained **5.725** pieces of 195 family members trained surgical material **18.354** mothers provided worldwide received (shunts, EVD, ...) a year's supply of folic acid **PERU** 775 children followed-up 8 new in 2023 17.450 catheters 41 professionals trained provided 2 clinics worldwide



SUDAN

22 family members trained

ETHIOPIA

337 children followed-up

253 surgeries

36 family members trained

KENYA

5.296 children followed-up

413 new in 2023

229 surgeries

76 professionals trained

897 family members trained

142 clinics

501 shunts

TANZANIA

2.953 children followed-up

825 new in 2023

702 surgeries

14 professionals trained

2.293 family members trained

51 clinics

201 shunts

MALAWI

3.027 children followed-up

468 new in 2023

606 surgeries

59 professionals trained

411 family members trained

111 clinics

551 shunts

SOUTH-AFRICA

1.262 children followed-up

29 new in 2023

24 surgeries

9 professionals trained

71 family members trained

"Here I am, confronted with a child with spina bifida for the first time. They tell the mother about the effects of this condition while caring for the baby.

What I see leaves me stoic and I feel a deep sense of compassion for this young mother.

She has to face this battle every day.

SHAU wants to give hope again to this mother.
They stand beside her from the first surgery in the hospital,
but also stay for post-treatment
and where necessary throughout the child's life."

- Daniil -







PARTNER ORGANISATIONS

♥ BethanyKids



SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION OF KENYA COAST BRANCH



































































COLOPHON

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

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I spend the afternoon with the children at the rehabilitation home. I realise that these are incredibly brave teenagers. I am touched by their calmness and resilience. - Daniil



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