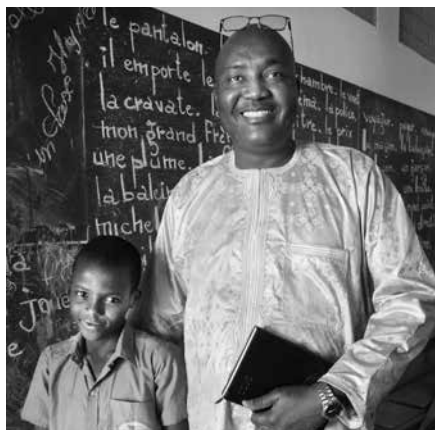


Interview with the Local Noma Programme Manager



The Sentinelles Programme in Niger is currently run by a team of 21 staff members, who run our reception centre 24 hours a day, 7 days a week, and monitor approximately 300 children in their living environment. Thanks to this team, which includes stewards, guards, cooks, drivers, nurses, social workers, animators, outreach workers and an administrative structure, the Centre has not closed its doors for a single day in 30 years, regardless of major security incidents in the country or during the Covid pandemic.

Ali Adah started working for Sentinelles 13 years ago as an outreach officer. He gradually evolved within our organisation to become an administrative assistant and then, in 2015, Local Head of the Noma Programme when Sentinelles decided to operate with a 100% local team.

Ali Adah, you are responsible for a team of 20 people and for Sentinelles' activities in Niger. How would you describe your role in three words?

In three words: I am an organiser, a planner and a coordinator.

What projects are you currently working on?

For some time now, an important project has been to strengthen and diversify our awareness-raising activities. In this area, we are also carrying out important communication work with partners in order to move towards good coordination of the actors involved in the fight against noma. Strengthening the resilience of the population, and particularly of children affected by noma, has always been our focus. It is a project that is constantly evolving, and we have recently strengthened our approach to implementing income-generating activities with the families we follow.

What are the main current and future challenges for the Zinder Centre?

I would say that an important challenge is already to strengthen the capacities of certain staff members in order to meet the ever-increasing demands in terms of the quality of care for the children and the monitoring and reporting of our activities. Another challenge is to continue to open up to existing actors who offer a complement to Sentinelles' activities in the fields of health, education, vocational training, etc. It is very important to strengthen existing partnerships and to continue our outreach to opinion leaders at the community level.

What do you like best about your work?

My favourite thing is to achieve the goals I set for the day despite the many demands. In other words, I am happy when my work is done well and on time. But if we talk about my favourite moments on a human level, then I would say it is when a child

and his parents find their hope and smile in life! I feel like time flies, every day is full of challenges. Sentinelles has made me a true humanitarian!

Can you tell us about the evolution of the fight against noma since you started working for Sentinelles?

We can look at it from different angles, but I choose to remain optimistic. For me, the fight against noma is evolving well because the population is starting to take its destiny into its own hands by going quickly to the nearest health centre as soon as it notices the first signs of the disease. We see this every day in our Centre with the consultations that follow one another. I would like noma to be included in the list of neglected tropical diseases by the WHO.

If you had a message for our loyal readers, what would it be?

You should share your joy and happiness with those who have lost them, as this will help them and guide them on the path of hope.

SENTINELLES
TO THE RESCUE OF WOUNDED INNOCENCE



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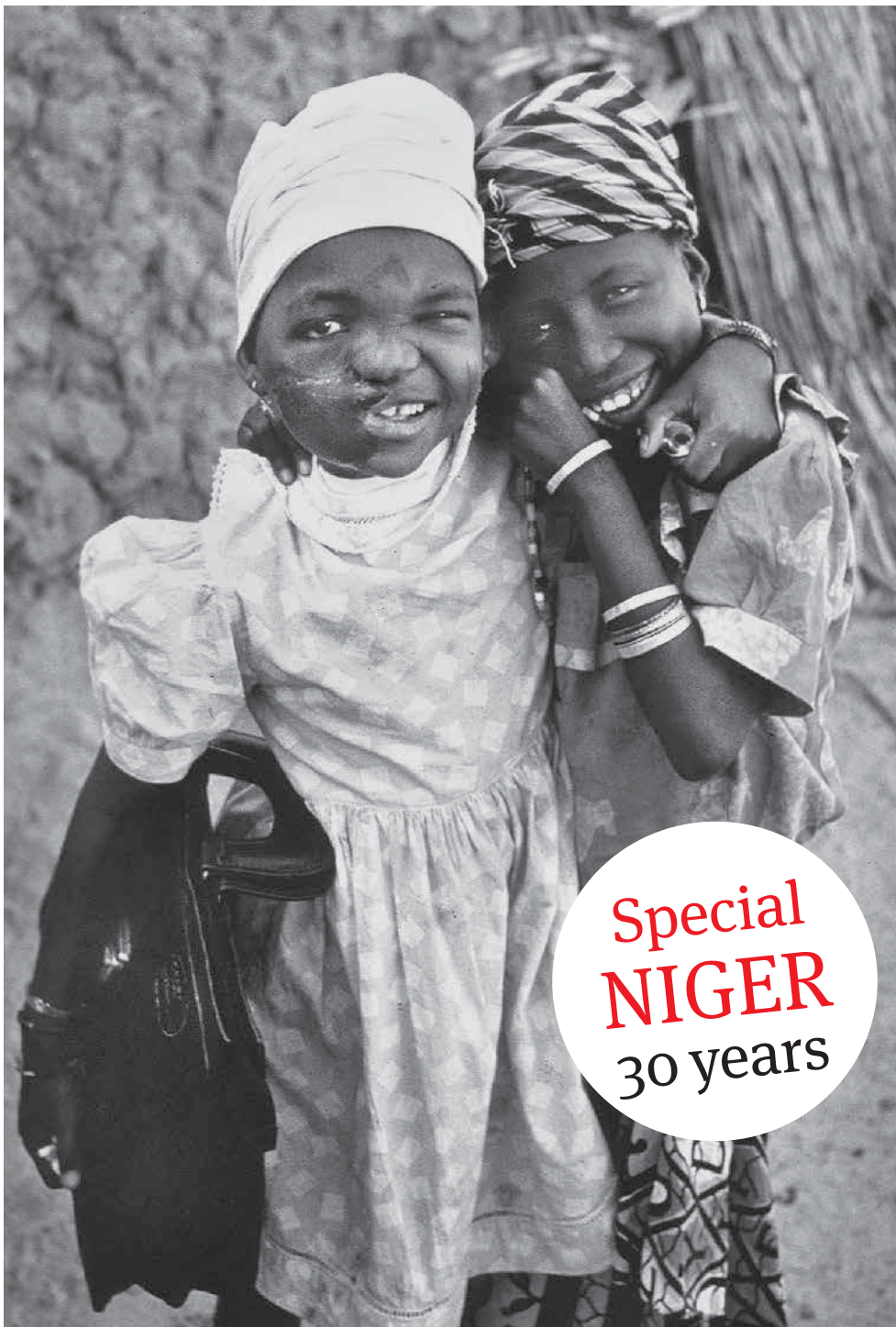
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SENTINELLES

TO THE RESCUE OF WOUNDED INNOCENCE

N° 283 / August 2022



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Professor
Denys Montandon: sewing
faces and lives

Three decades of the fight
against noma

Testimony of the local
programme manager

Edito

Niger, Noma and Sentinelles, 30 years on

In 2020, Niger experienced its first democratic changeover since independence, and over the past decade, the government has been able to boast positive results in terms of child enrolment in school and poverty reduction. However, the country's significant population growth offsets these achievements. The country regularly occupies the last place in the world ranking according to the human development index. Moreover, since 2013, terrorist attacks, inter-community violence and food insecurity have weighed on the population and weakened the social cohesion traditionally cultivated by Nigeriens.

Zinder, where Sentinelles was established 30 years ago because of the high number of children with noma in the area, is constantly faced with the shock of the lean season. Last year's harvest was not good due to a severe lack of water; millet stocks in particular are running out. Despite state support for the most vulnerable, many families are affected by food and nutrition shortages. Noma is likely to have a bright future ahead of it.

This is why it is imperative to continue to raise awareness, to deploy innovative actions to inform the inhabitants, to train health workers and to allow for the early detection of the disease. In this way, lives will be spared and suffering avoided. Schoolchildren, villagers and representatives of civil society, armed with their knowledge of the disease and its rapid evolution, will themselves become actors in the fight against noma, the Sentinelles.

With your indispensable support, united by the same desire to prevent noma, we will make a difference.



Noma, a devastating disease

“The head devoured, bloody, upset, out of sorts, jaws welded together, the eye often cut, in the bush or in a village, not sought after - therefore not found - without means since they have nothing, and without rights since their parents, who are poor, do not know that the poor have rights, such are the children affected by noma, thus barely described.

What we do know is that, if detected in time, noma would heal in the first week in these very young children. But as no one knows anything, and the health ministers do not inform their medical and social services, nor the population, this disease is devastating. Without, however, striking its victims, children with faces bursting with suffering. It is up to us to bear the shame of it. Who do nothing, or so little.”

Edmond Kaiser / 1992



Schooling and vocational training

We do our utmost to give access to education to all the children we follow, despite the great difficulties they face in obtaining quality schooling outside the urban Centres. A large proportion of them go to school in their villages. To give them more chance, we have recently developed three partnerships with quality schools in Zinder, which for the moment allow nine children to attend school there. Four young people have recently been trained in trades such as sewing, mechanics and carpentry in one of these schools.

The challenge of prevention

Previously focused on raising awareness in the villages, we now want to reach more people in a more sustainable way to prevent the disease.

Sentinelles has therefore launched radio awareness campaigns and trains community relays and traditional practitioners in the early detection of noma.

Since then, consultations have increased drastically at the Centre as have telephone calls from health workers and community relays. The difficulty of accessing basic care and the high level of poverty of people who bring their children for treatment have encouraged us to make gingivitis treatment free of charge, in order to prevent it from turning into noma.

It was thanks to a radio message heard by a neighbour that Malika's mother brought her daughter to the Centre at the beginning of May. When she arrived, the whole left side of her face was swollen, and her eye was completely closed. Thanks to the care she received, she recovered very quickly, and the disease did not leave any physical damage.

Mariama, aged 5, arrived in the summer of 2020 with a very severe noma that formed a large lesion on her face. This year, she is at the Centre with Malika because she is here for an adaptation period before her departure for Switzerland. She will be operated on several times by the plastic and reconstructive surgery team of the HUG. The two girls take part in the lessons given by our teacher and often have fun with Fassouma, Rabaha and Habsa, who attend a boarding school in Zinder.

In the complicated socio-economic and security context of Niger, Sentinelles' activities to fight noma continue to give hope to children and families who have extremely few resources to meet the heavy challenges of their daily lives.



Malika, accompanied by her mother and her little sister at the reception Centre

30 years later... Malika, aged 9, arrives at our Centre in Zinder.

She is the 1,380th person with noma that Sentinelles has taken care of since 1992. It's a simple fact: children with noma are still arriving and there is still a clear need to take care of them. Our goal is to accompany them on their life journey.

What do our activities look like 30 years later?

Although Sentinelles' mission has remained intact, many changes have taken place in the activities, both to improve the monitoring and care of children and to contribute to the prevention of this disease. Here are some insights into the noma programme, 30 years after its inception.

Medical care for children, from first aid to reconstructive surgery.

When they arrive at the Centre, children with noma are cared for by a team of nurses. Some do not develop external lesions, like Malika. Others are less fortunate and arrive too late to avoid tissue necrosis. These children with sequelae are followed for several years until they can benefit from reconstructive surgery. Before, they were transferred to Switzerland to be operated on by a team of specialists. Surgical missions were also organised in our Centre in Zinder. At present, almost all the children are operated on in Niamey in collaboration with a partner NGO and only a few really complicated cases are transferred to the University Hospitals of Geneva (HUG), with whom we maintain a close collaboration and valuable links.

The Centre has recently undergone extensive renovation, which has enabled us to refurbish the infrastructure and renew certain equipment. These major works have brought a breath of fresh air and modernity, improving the quality of the children's stay as well as the working environment of the 21 staff in the programme.

Social follow-up of children and their families

The follow-up at home of the cured children is carried out by social workers who visit the families scattered throughout Niger. Particular emphasis is placed on the adoption of good personal and environmental hygiene habits, encouragement to seek basic care when the child is ill, and schooling. Income-generating activities, ranging from small trade to animal husbandry, are set up and monitored in some families.



Consultation/detection of gingivitis



Sentinelles reception Centre in Zinder



Adbou can finally have access to school



Noma awareness session



1992, Exploratory mission in Niger

Letter from our delegate:

“Zinder, 17 September 1992

Today the research in the Zinder region is over, full of sad discoveries, confirming the immense work still to be done.

Often nobody really cares about these little ones. Some, discharged a few weeks ago from hospital, have already died. Others, with their jaws closed and completely blocked, have only their eyes to cry.

We found Nana, a tender-looking girl of thirteen, in her village, her face and mouth in full infection, untreated, and in great distress. We immediately admitted her to hospital, and she is already much better today.”

Our delegate’s report continues with an alarming tally. In a radius of 40 km partially visited around the capital Zinder during one week, from village to village, search for children affected by noma and other facial mutilations.

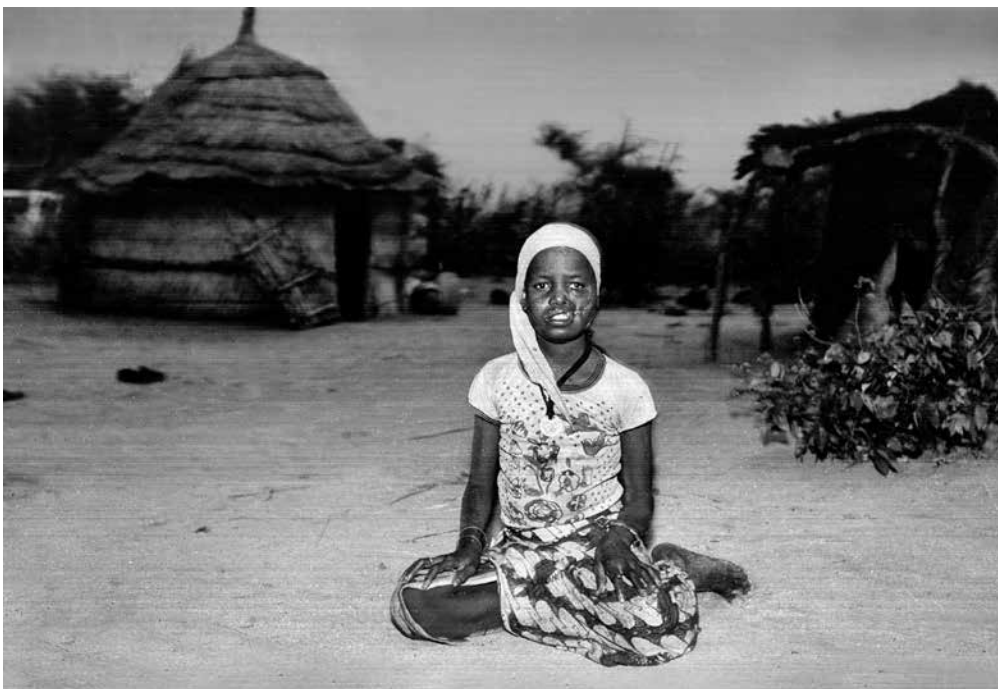
Noma:

9 children with sequelae and total contracture of the jaws (fused jaws), 2 with sequelae and partial contracture, 7 with sequelae without contracture, 6 without severe sequelae and 4 without sequelae. 2 children reported by the hospital in Zinder but not found, and 4 children who died, sometimes a few weeks after their release from hospital.

Other facial mutilations: 7 children found.

Total: 41 children.

Going through the whole province and all the provinces, one can imagine...

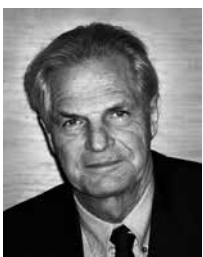


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This is where it all started



Professor Denys Montandon,
President of the Friends of Sentinelles
Former Head of the Department of Plastic,
Reconstructive and Aesthetic Surgery at the
University Hospitals of Geneva (HUG)

When in 1986 I was called to the paediatric ward of the Cantonal Hospital in Geneva to see two severely disfigured girls who had been transferred from West Africa and hospitalised through Terre des hommes at the request of Edmond Kaiser, I had no idea that these children and this disease, noma, which I did not know, would occupy me and above all preoccupy me for decades.

Several complex operations were necessary to give back a shape to these faces, so that these children could go back to their families. These were exceptional cases, the likes of which I would never see again, I told myself. However, this was not the opinion of Edmond and Yvan Muriset, who had learned from the International Dental Aid that many other little girls and boys were suffering or dying from the same disease, in great destitution, particularly in the Zinder region of Niger (children discovered during the Sentinelles exploratory mission in September 1992).



Life story of one of the first children discovered in 1993 and rescued by Sentinelles at the opening of the noma program.

“The mutilation of the face was so rapid that no one understood it. The after-effects are such that he has lost a large part of his face, including his nose. The destruction is 5 cm wide, 5 cm vertically, and 6 cm from the left corner of the lips to below the right eye. The contracture of the jaws is partial, but the lack of facial muscles makes chewing difficult.

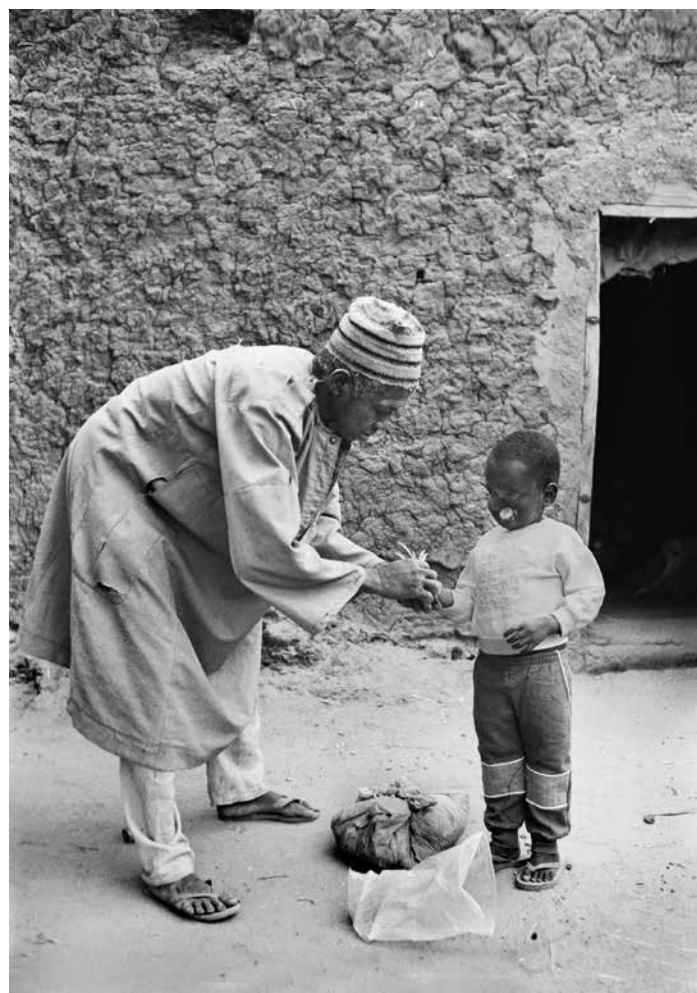
It was during the rainy season that Kaka Landou (his guardian) and other family members noticed a certain discomfort in the child, who was then five years old. When it rained, he would sit in front of the door, leaving it open. When the door was closed, he would start crying so much that they had to open it again. He would then take some wet earth and put it on his head and thighs.

After the rainy season, his cheeks began to swell and a large pimple appeared. Nine days later, his face started to crack, first on his lips and then on his nose. Kaka Landou himself took him to Galmi Hospital, 45 km from his village. He did not want to listen to the healer whom he did not trust. The child stayed in Galmi for two months, but although he was treated, he soon lost part of his face. The guardian did everything possible to ensure that Nassourou recovered. He even sold his field and garden to pay for the treatment. One of the bills from the Galmi hospital amounted to FCFA 35,000 (CHF 185.-).

The people around him perceived the phenomenon as a curse, especially since the child had never had any problems. He was always healthy, always ate well and always had lots of friends, which he still has today. The only shadow is the emigration of his father to Nigeria when he was three years old.

Nassourou is now being followed by Sentinelles, who is organising an upcoming operation. He is very attached to his uncle and guardian and very much loved in the village. There is no difference between him and his friends. Despite his illness, Nassourou is often in a good mood, as we saw for ourselves during our last visit.”

Little Nassourou, 6 years old,
suffers from noma. He lives in a village
half an hour's walk from Madaoua,
400 km from Zinder.



And that's where it all started.

A small house, two vehicles, medical equipment and, above all, a dedicated medical and social mini-team; 10, 20, 30 children could be taken in and cared for. As soon as the Sentinelles Centre in Zinder was created, I wanted to go and see the local situation for myself. Accompanied by Brigitte Pittet and Alexandre Jaquinet, I spent a few days in this corner of the Sahel, meeting and examining the sick children, visiting the hospital, and discovering some of the surrounding villages where patients had been reported. The extreme poverty of the country did not fail to shock the privileged people that we are, but it also allowed us to admire the energy of these women and men who have to struggle to find enough food for themselves and their children every day.

This first mission allowed us to evaluate the possibilities of surgical treatment in the hospital in Zinder, taking into account the safety of the equipment and the post-operative follow-up. It was immediately clear that a number of small patients could be operated on, provided that missions were organised with surgeons, anaesthetists and nurses with adequate medical equipment. For others, when the risk of death was too high or the number of successive operations prevented local management, it was preferable to operate in a highly specialised medical centre. For the latter, the agreement signed between Sentinelles (at

the time Edmond Kaiser and me) and the HUG (University Hospitals of Geneva) was of great importance and made it possible to treat several hundred children under better conditions over the years.

Noma disease, which eats away at the faces of the poorest children, is not new, as texts from Egypt and ancient Greece show.

“If you see a man who has a hole in his cheek, very swollen all around, with a black area that comes off and will fall off, then you must say: This man who has a hole in his cheek, this is a condition that I must treat. You must bandage him and apply oil and honey every day until he is well.”
Egyptian Papyrus of Smith
1650 BC

It was also found in Europe until the last century. It has always been closely linked to poverty and malnutrition.

But no serious study on the origin of this non-contagious infection had been undertaken. Thanks to the financial support of the Hirzel Foundation and the unconditional support of Sentinelles, research on more than 80 children recently infected with the disease, compared to healthy children of the same age, has made it possible to determine the type of bacteria involved in the onset of the disease,

as well as the social and family conditions in which they were most prevalent. Under the direction of Dr Denise Barrati and Professor Didier Pittet, this study, which lasted more than ten years, showed that there was not one bacterium responsible, as in other infectious diseases, but an imbalance of germs in the oral cavity. The study confirmed the role of malnutrition in the occurrence of noma, and that it mainly affects the last children of a large sibling group.

More than three decades of working with Sentinelles to fight noma cannot be summed up in a few lines. To work with Sentinelles, whether as a surgeon or as a simple supporter, is to adopt Edmond Kaiser's motto with conviction: “If I know that a little person needs a face and a breathable life restored, I will give it to him.”

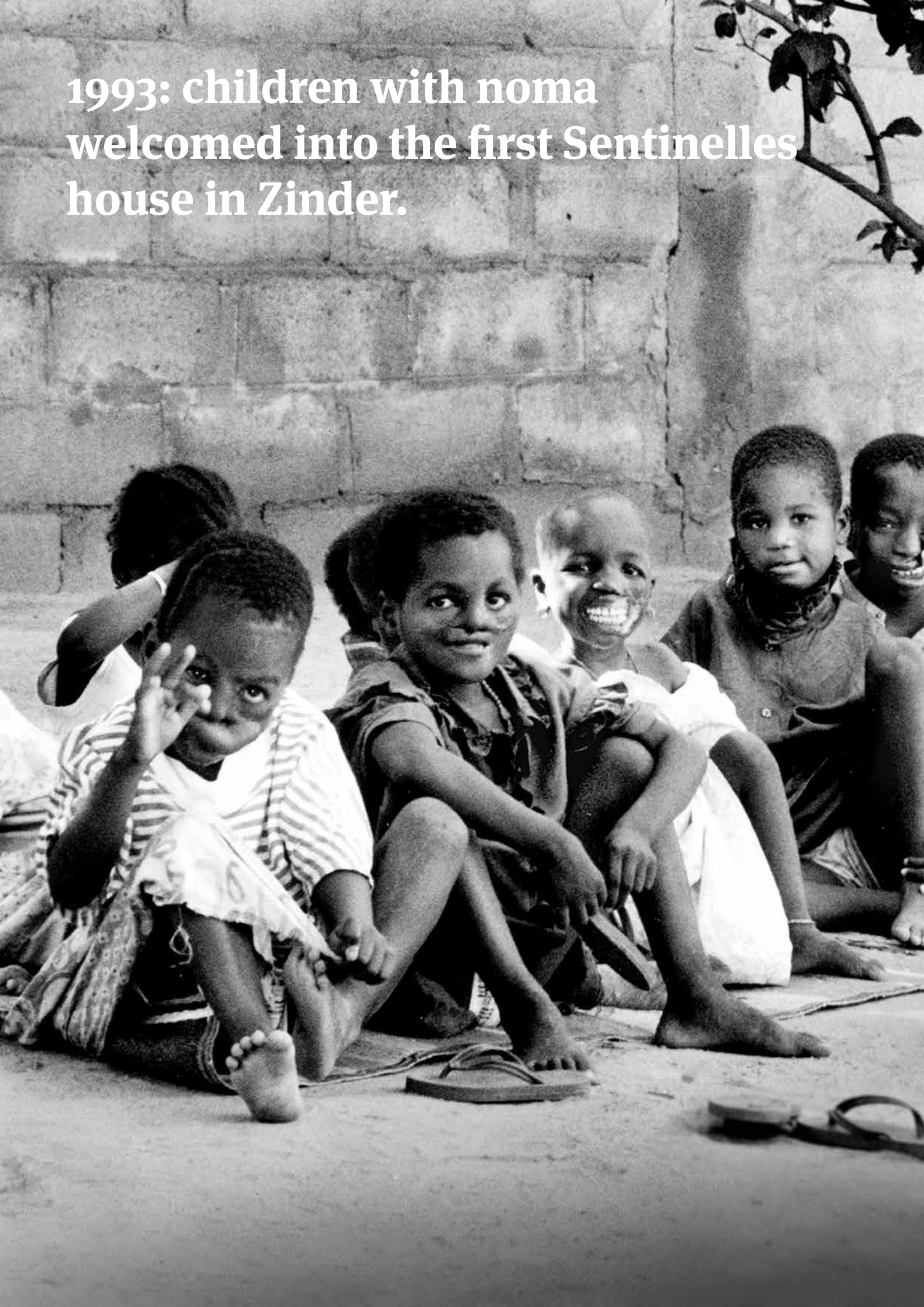
Giving a child suffering from noma a breathable life means not only treating and operating on them, but also accompanying them throughout their life so that they can regain their human dignity in their family and in society. This is Sentinelles' mission.

Little Sabiou is one of the many children suffering from the serious after-effects of noma, inoperable on the spot, who has been able to regain some of his face and his smile thanks to the surgical treatments carried out at the HUG. In order to continue the early detection of noma, the vital care and the individual follow-up of each child under care, we need your help.

Thank you for your precious support.



**1993: children with noma
welcomed into the first Sentinelles
house in Zinder.**





“Maybe terrifying things are just helpless things waiting for us to rescue them.” *Rainer Maria Rilke*