

*SENTINELLES*

*That everyone should be aware  
and wake up*

*Assisting wounded innocence*

*Aid programme for children  
suffering from noma in Niger*



*Year 2012*

## 1. Introduction

Since the end of 1992, SENTINELLES has been working in Niger with children suffering from noma, a devastating disease that devours their faces and their heads until death occurs. Very often victims of rejection by their families and not receiving the appropriate medical assistance, they remain in extreme physical and psychological distress. Sentinelles' Reception Centre and offices are situated in the town of Zinder, nearly 1,000 km from Niamey.

### *Niger in a few figures*

Sentinelles' actions are essentially concentrated in the East and the Central regions, principally in the region of Zinder, which covers a surface of 146,975 km<sup>2</sup> (3.5 x the surface of Switzerland), that is about 12.4% of the national surface area and the population represents 18.8% of Niger's population.

Niger's population is estimated at 16,274,738 inhabitants. The fertility rate is 7.16 births per woman, infant mortality (before 1 year) is 110/1,000. The literacy rate is estimated at 28.7%, of which only 15.1% are girls.

Agriculture employs 87% of the active population and 82% of the population live in rural zones. More than 60% of the population live beneath the poverty line and 35% beneath the level of extreme poverty. Life expectancy is 54.8 years for women and 52.9 years for men. About 28% of the population is undernourished.

## 2. What was achieved in 2012

The aim of our work is to ensure that the children benefit from their fundamental and emotional rights : food, medical treatment, schooling, professional training, work and preparing them for their independence.

Taking charge of a child entails close individual accompaniment in the long term.

- ***Following children in the bush.*** At the heart of the follow up procedure, the desire to keep children in their families if circumstances permit.
- ***Individual aid.*** According to his personal situation, each child receives affection and the medical, food and social help required. A multiplying effect is sought when social aid is granted so that the child's family can also benefit.
- ***Reception Centre.*** The nerve centre of the procedure for following children in the bush: the Reception Centre in Zinder allows for temporary accommodation for the children and those accompanying them in order to resolve medical or social problems.
- ***Detection and awareness raising.*** At the Reception Centre and during visits in the bush, teaching about nutrition, health and hygiene destined for the children and those accompanying them. Weekly public consultations to detect gingivitis are organised by Sentinelles for the population, free of charge. These also allow for the early detection of noma and other oral infections.

- **Prevention.** The work of prevention undertaken since 2004 with members of the health structures came to an end in February 2010. It was followed by awareness raising actions with the usual village authorities and the population. In 2012 this awareness raising programme took place mainly in the region of Zinder and the departments of Magaria, Mirriah and Kantché.
- **Physionoma.** This association was created in 2003 following serious reflection on the necessity for re-education and postoperative care for children victims of noma. In 2012, an individual report on each child following intensive physiotherapy was sent to the Association each month.
- **Treatment for children in Europe.** Children suffering from very serious sequels, inoperable on the spot, are transferred for the most part to Switzerland, where they receive surgical treatment (reconstructive and maxillofacial surgery).
- **Surgical missions.** In collaboration with Professor Brigitte Pittet-Cuenod from Geneva University Hospital (HUG), a mission was possible in Niger in January. In addition, three missions for children suffering from a labial and/or palatine cleft were possible in collaboration with Dr. Jean-François Negrini and the CURE Children's Hospital in Niamey.

*« Take the other one in your arms and try to console him.  
 Try not to hurt him.  
 Be lucky enough to keep his youthful freshness and his wonder.  
 To "grown-ups" prefer the stars,  
 music, the Child, animals, human voices,  
 flowers and their perfume, love.  
 Let the nightingales sing »*  
 Edmond Kaiser



### 3. Aid work

The programme in Niger ensures taking care of 718 children, of whom 427 are spread out all over the Zinder region and 291 are children living outside its borders (Niamey and its region, Tillaberi, Dosso, Agadez, Maradi, Tahoua, Diffa, from Benin, Nigeria and Chad).

Zinder region	Noma	Harelip (*)	Other regions	Noma	Harelip (*)
Gouré	6	29	Niamey	2	2
Magaria	24	67	Tillaberi	2	2
Kantché	19	30	Dosso	2	
Mirriah	94	64	Tahoua	81	43
Tanout	15	17	Maradi	39	67
Zinder commune	29	33	Agadez	1	11
			Diffa	7	9
			Benin	1	
			Nigeria	7	14
			Chad		1
<b>Total no. children</b>	<b>187</b>	<b>240</b>		<b>142</b>	<b>149</b>

(\*) Harelip, otherwise known by the name of labial and/or palatine cleft.

#### a. Individual aid in 2012

All the children suffering from noma are followed on a medico-nutritional, family and social level during visits in the bush or when they are staying at the Reception Centre. Those suffering from a harelip receive a medico-nutritional follow up and some of them also need social accompaniment.

The children stay at the Reception Centre the time necessary to prepare them medically and psychologically for the surgical missions organised on the spot, or for their transfer abroad and their reintegration in the country on their return.

In Zinder, and during awareness-raising sessions in the bush, we also offer free oral hygiene check ups, which are open to the public and allow us to detect in time many children who are at risk of developing noma, in particular those suffering from gingivitis.

#### *The Reception Centre in Zinder*

The Reception Centre allows us to take in on average 80 to 100 children and adults ranging in age from a few days to 45 years and sometimes more, whose condition,

notably in cases of the acute phase of noma, demands treatment that the local health services are not able to provide. Children between the ages of 2 and 6 are the most numerous.

In 2012, each month on average 90 children and adults passed through or stayed at the Reception Centre; 58,713 meals were served to the children and those accompanying them and staying in the Reception Centre. They receive daily medical check ups. Physiotherapy sessions for those suffering from contracture of the jaws are provided three times each day; for some, the use of a wedge is indispensable to maintain the mouth opening. This facility also allows us to prepare them in anticipation of surgical treatment abroad and on their return, as well as when their family or social situation so demands.

In the Reception Centre, a treatment room allows us to provide basic treatment (dressing wounds, antibiotherapies, renutrition, rehydration, antimalarial treatment, elimination of parasites etc.), to vaccinate the children and to carry out minor medical analyses. The children are treated for very diverse complaints: gingivorrhagia, the acute phase of noma, ophthalmic problems, infections, otitis, diarrhoea and bronchitis.

The treatments are complemented by lessons on health, hygiene and nutrition, destined for the children and those accompanying them (mothers, grandmothers, fathers, grandfathers...)

In 2012, we continued awareness-raising on the following themes: traditional practices that are harmful to the health of the mother and the child (early marriage and childbirth and their consequences, excision and female genital mutilation, food taboos, neglecting the first child, hygiene measures), vaccination, weaning (stages of weaning), spacing out of births, leaving to work elsewhere, AIDS, protecting small children from the cold and malaria (causes, protection measures).



Awareness-raising session at the Reception Centre

This year we took in and treated 41 new children and adults suffering from noma, without counting all those who had not been included in the follow up procedure as their benign sequels could be treated in outpatients thanks to the consultations to detect gingivitis. Of the 41 children discovered, 23 come from the region of Zinder, 9 from the Tahoua region, 6 from Maradi region, 1 from Tillaberi region, 1 from the Agadez region and 1 from Nigeria.

### So many children are still waiting...

Since the beginning of our work of aid in Niger, nearly 930 children and adults suffering from noma have been taken in hand. The last half of 2012 was particularly difficult, the number of children in the acute phase of noma discovered each month doubled. On one hand, this was due to the fact that cases of malnutrition in the mothers and small children were hardly improving and on the other hand thanks to the meticulous and persistent work of Sentinelles' teams in the bush.



We discover **Sabiou** on the 22<sup>nd</sup> July. He is 5 years old and comes from the little village of Gagaré. He is suffering from noma in the acute phase, with loss of tissue from the left side of his face, destruction of the bone of the nose affecting the left eye, damage to the middle of the upper lip and a third of the lower lip.



**Zeinabou** was discovered last August, she is 3 years old. She comes from Kirya, department of Tessaoua, Maradi region. When she arrived at the Reception Centre, Zeinabou's state of health worsened ; she shows a loss of tissue from the middle of the face up to the right eye.



On 2<sup>nd</sup> October **Samawilou**, 2 years old arrives in Zinder at the Reception Centre. On arrival at the Centre, Samawilou shows a loss of tissue from the left cheek. He is malnourished.



We discover **Mahamadou** in November. The little boy is 3 years old and he is suffering from malnutrition and noma in the acute phase with a loss of tissue from the right cheek and a third of the lower and upper lips.



In December, we go to fetch little **Issaka** as a matter of urgency. 5 years old, he is hospitalised in Dakoro District Hospital. When we arrive at the hospital, we discover a very weak little boy, malnourished and anaemic. He is suffering from noma in the acute phase, both cheeks damaged, but also with a congenital malformation of both feet.

82 new children suffering from a harelip were also taken in charge. Of these 82 children discovered, 12 children were born in 2011 and 34 in 2012. Most of these children, accompanied by their mothers, benefit from an intensive follow up of their diet (supervision of breastfeeding) and their general state of health.



Deaths are many amongst very small children suffering from a labiopalatine cleft, because of the problems encountered with feeding. Sucking, and as a result feeding baby (breastfeeding or bottle feeding) become difficult. The divided lip and palate are practically incapable of ensuring a watertight join because of the communication between the oral and nasal cavities. In addition, as the mother's breast is not stimulated by sucking, in many mothers the milk does not rise. As for artificial milk, it is much too expensive for a family living in the bush in Niger.

Sustained supervision of breastfeeding for babies having trouble in suckling is put into place as soon as the mother and her child arrive. A nurse specifically trained for this follow up is responsible for the little ones under "supervised breastfeeding".

Another nurse is responsible for basic vaccinations for these very small children, in this way limiting infantile diseases that can lead to the death of babies already made fragile by the congenital malformation and the malnutrition from which many of them suffer.

- *1'064 children were taken into the Centre in 2012 for stays ranging from one day to several months. Some of them were taken in several times during the year.*
- *264 children had a consultation to detect gingivitis during the year.*



In 2012 no mission by the Association *Physionoma* was possible, as the security situation in the country would not allow this. However, individual reports on each child operated on for permanent constriction of the jaws and having to practise intensive physiotherapy were sent monthly, allowing the Physionoma team to continue to follow the children and the work of the Niger team on a regular basis.

### ***Follow up of children in the bush***

The procedure for following children relies on daily journeys into the bush by social workers and by nurses if this proves necessary. Each team has the use of an all-terrain vehicle.

### ***Periodicity of visits in the bush***

Depending on distances (the journeys vary from a few kilometres to trips lasting for more than 2 days), the season and the condition of the vehicles, the teams visited on average 98 children each month. During the year, the **1,176** home visits carried out represent almost 10,000 km covered each month in the bush with the two operational 4x4 vehicles. The frequency of the visits is linked to the personal, medico-nutritional, family and social situation of each child. The objectives of the follow up in the bush are to :

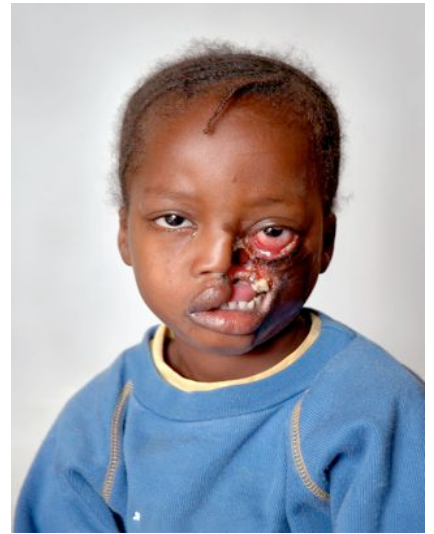
Provide basic treatment; direct or take children or a member of their family to a dispensary, a hospital or to the Reception Centre; get to know each child better and discover his needs; assess the aid necessary in relation to local possibilities; to provide material aid; to complete and bring up to date the medico-social inquiries; take the administrative steps linked to school enrolment, social benefits and the transfer of children to be operated on in Europe.





## Zeinabou, 10 years of accompaniment

In September 2002, we meet Zeinabou, hospitalised in Galmi Hospital, Niger for 11 days and accompanied by her maternal grandmother. Zeinabou is 2 years old, suffering from noma in the acute phase and her condition is critical. Zeinabou arrives in the Reception Centre where she is immediately taken in hand for emergency medical treatment. Five months of intensive treatment were to follow, daily oral care, cleaning of the wounds, dressings, renutrition, rehydration, until she came back to life and good health. However, Zeinabou's face was completely destroyed : total loss of soft tissue from the left cheek, from the upper lip, the wing of the nose, slight damage to the left lower eyelid. The upper jawbone was damaged. The nasal bone too. In addition, she was suffering from constriction of the jaws, one of the most serious sequels to noma.

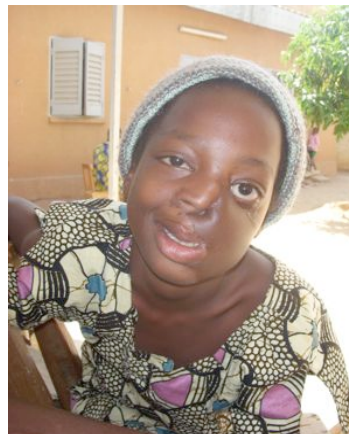


Between 2003 and 2005 Zeinabou, completely cured, received frequent medical and oral check ups. These visits to the family, once per month for Zeinabou in 2003, entailed a journey of 450 km to go there and 450 km for the return journey.

From 18<sup>th</sup> March until 22<sup>nd</sup> August 2006, Zeinabou was transferred to Switzerland, where she would be taken in hand by Professor Pittet's team from the HUG : 1<sup>st</sup> operation for the reconstruction of the cheek and the nose with a free flap from the right latissimus dorsi muscle, with a skin graft taken from the scalp. 2<sup>nd</sup> operation for commissuroplasty and adjustment of the flap.

In August 2006 Zeinabou returned to Niger. There was an important medical follow up to be done : treatment to her mouth, physiotherapy three times per day, a drainage tube to be worn in her left nostril 24 hours a day and daily cleaning of the tube, wearing a wedge 24 hours a day so that her mouth did not close up again and massaging the flap and the scars with a greasy cream three times per day. All treatment was accompanied daily by a nurse from Sentinelles.

In 2007, having rediscovered her smile, Zeinabou was enrolled in her village school. In 2009, we granted a loan to Zeinabou's father to buy animals for fattening and resale. In 2010, frequent medical check ups continued. Zeinabou was again seen by Professor Pittet during a surgical mission. In 2011, given the family's extreme poverty, we gave a little help to the mother, a small business. As each year we organise courses for school follow up and support during the two summer months, Zeinabou was able to participate in the summer of 2012. During this year, we continued to check her mouth opening, her flap, her nostril, which must not close again. Today Zeinabou is twelve and full of life.



**« You become forever responsible for those that you have tamed »**

*Antoine de Saint-Exupéry*

### ***Method of distribution of individual aid***

All the children received medical help : follow up of their general and local condition, physiotherapy and the wearing of a wedge, hygiene, as well as prescriptions for medicines and vaccinations.

- 45 *mosquito nets* were distributed. All the families visited were made aware of the fight against malaria.
- 83 children are followed in their schooling, of whom 68 are in primary school and 15 in secondary school. 53 of them have received help for *school materials*. 16 children have received a loan for *basic schoolbooks*. 1 pupil had his schooling paid for him and another had kindergarten paid. Expenses for the School Management Committees were also covered. During the summer holidays, 39 children followed *school support courses* organised within the Reception Centre.
- 1 child is training as a motorcycle mechanic. 4 young women are following *dressmaking training* in a workshop or a training centre. 2 young women are enrolled in a *health training school*.
- 223 *nutritional aids* were distributed in the form of food, which represents 882 50kg sacks (millet), 4 sacks of rice and 10 measures of beans. Included in this aid is millet given in cases of placement outside the family for reasons of schooling or training. Several methods of distribution are put in place depending on the social and economic situation of the families that we follow : gift, payment in cash at lowest cost price, reimbursement in cereals of 50% after harvest, reimbursement in cereals of 100% after harvest.
- 10 children and their families have received *social aid* with the necessary supervision.
  - 2 helped with animal breeding (purchase of ruminants)
  - 1 aid for off season crops
  - 1 aid with agriculture (purchase of a field)
  - 5 received help for a small business
  - 1 received help to build a room
- Many children also receive *clothes and toys*, depending on their needs.

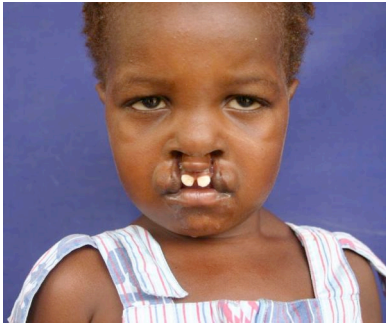
• The overall satisfactory situation of 29 children suffering from noma allowed us, during 2012, to bring their follow up to an end. We lost sight of 2 children. We mourned the death of 1 child in 2012.

• The satisfactory medical situation of 76 children suffering from a harelip allowed us to close their file in 2012. We lost sight of 1 child and mourned the death of 12 children, as their medico-nutritional condition had been so precarious.



## b. Surgical interventions in Niger

Some children and young adults who show slight to moderate sequels, or sometimes more important ones, but which do not call for a transfer abroad, are operated on in Niger during surgical missions.



In 2011, a new collaboration was born between Sentinelles and CURE International "Children's Hospital in Niger", an

American NGO created in 1996, whose objective is to heal children suffering from handicaps in developing countries. During 2012 this collaboration has allowed for operations on children and adults suffering from a labial and/or palatine cleft during 3 surgical missions (in April, June and October). These missions permitted 75 children and adults to be operated on.



*Everyday life,  
offers twofold evidence,  
that of suffering and that of consolation.  
In each other's arms.*

*Edmond Kaiser*

In January 2012, a mission led by Professor Brigitte Pittet (HUG) allowed for 32 surgical interventions (that is 14 children suffering from the sequels of noma and 18 from a labial and/or palatine cleft).



On a surgical level, the expertise of Dr. Martin in the pedicled submental flap, allowed us to treat complex situations and to avoid transfer to Switzerland for some of them. This mission also took place within the CURE Hospital in Niamey. This precious and constant collaboration allows us to hope that a greater number of children followed by

Sentinelles will be able to have operations in Niger, so avoiding transfer to Europe.



### c. Surgical interventions in Europe

Since 1993 Sentinelles has been working with the University Hospital, Geneva, and then also with other hospitals and surgeons to treat children from Niger suffering from serious sequels to noma. To be able to carry out these particularly difficult and complex operations, it is imperative to bring together different surgical specializations and state-of-the-art technology. A complete treatment for a child generally requires several interventions. In 2012, 4 children and 1 adult suffering from very serious sequels to noma were taken in charge for the transfer to Switzerland.

Four hospitals participate in the medical care of these children (3 for quarantine assessment and 1 for surgical treatment), in collaboration with Professor Brigitte Pittet (HUG) and Dr. Jaquinet from the Genolier Clinic.

### d. Other help

Alerted to their profound distress by them, themselves, or when our paths have crossed, they are without help or options. We cannot just pass them by...

#### *Maliki*

Maliki, born in 2002, suffers from total constriction of the jaws and scars on the right hand side of the face. He was transferred to Switzerland to relieve this constriction in 2011 and came back to Niger in February 2012. Today, we follow him for intensive physiotherapy.

#### *Zeinabou*

Zeinabou, born in 1993, suffers from Von Recklinghausen neurofibromatosis, hydrocephalus and epilepsy. She was operated on in Switzerland in 2008. In 2012, we continued to follow her for epilepsy and we provided the medicines necessary.

#### *Saliou*



Saliou, born in 2004, is a child suffering from noma and coming from Senegal. He was operated on at the CURE Hospital during Professor Brigitte Pittet's surgical mission.



We took him into our Centre for 3 months for postoperative care. Despite his inability to understand Haoussa, he became well integrated into the life of the Reception Centre.

And so many other children needing the urgent medical care given in our Reception Centre.

### e. Prevention / Raising awareness

From its establishment in Niger until today, Sentinelles has observed that the number of children touched by noma has unfortunately not declined. The health workers, the authorities and the population do not know this disease, or at least not well enough. Deaths due to noma in the villages are generally not registered as such and remain more often than not undeclared.

The first phase of the programme begun in 2004 came to an end in February 2010. From March, thanks to the precious support of the Foundation Winds of Hope, a second phase of awareness raising has been put in place, this time targeting the traditional community and the village populations.



Conscious of the power and the influence of the traditional community on the population, a team of two collaborators (covering almost 5,000 km per month with the help of a 4x4 vehicle), a community worker and a driver travel daily from village to village, neighbourhood to neighbourhood. Consultations to detect gingivitis are also offered to the village populations and when practical and meteorological conditions permit, an awareness raising film is shown at nightfall to the whole community.

#### Principal traditional practices harmful to the health of women and children

- ❖ Ablation of the uvula
- ❖ Excision
- ❖ Food taboos
- ❖ Extraction of the milk teeth
- ❖ Blood-letting
- ❖ Piercing the lower belly
- ❖ Scarification
- ❖ Tattooing
- ❖ Early weaning
- ❖ Early marriage and childbirth

So, the second phase of raising awareness is a mass sensitization, which directly touches all members of a village or a neighbourhood. It aims to raise awareness with the local authorities (the village chief and his court), the traditional authorities (the traditional healers), the religious authorities (imam and marabout), the moral authorities (teachers) and the population.

The specific objectives are to raise awareness of the disease noma, early detection of the disease and the reflex to rapidly seek medical treatment, the promotion of oral hygiene,



the promotion of teaching on nutrition, the promotion of cleanliness in the home and the vaccination of small children.

In 2012, 6'041 of the people targeted were touched by awareness raising campaigns, principally in the departments of Magaria and Kantché in the Zinder region. In addition, about 5,030 villagers participated in these sessions. 48 students and 252 NGO

personnel took part in training sessions on noma. Moreover, 44 health structures received posters and documentation on the disease.

Village Area	Area Chief Village Chief	Traditional practitioner	Midwives	Imam Marabout	Health worker	Teacher	Total People
349	354	45	675	4'891	60	16	6'041

During the awareness raising sessions within the villages or neighbourhoods, 464 children were found to be suffering from gingivitis, 2 children suffering from noma and 10 with a harelip.

With regard to the awareness raising film, 11 showings were possible with the participation of about 3,200 villagers. At the time of these projections, 41 children were found suffering from gingivitis and 1 with a harelip.



## 4. Sentinelles' team in Niger

A team of 25 collaborators work in Niger in the framework of this programme, ensuring both the 24h/24h running of the Reception Centre in Zinder and the medico-nutritional and social action in favour of children followed in the bush.

<b>Work sector</b>	<b>Function</b>	<b>No.</b>
Management	delegate responsible for Reception Centre	1
Administration	administrator	1
Care in the Centre	nurses	8
Animation in Centre	animator	1
Upkeep of Centre	housekeeper, cooks, cleaners , guardians	7
Follow up in bush	social workers	3
Awareness raising	animator	1
Logistics	drivers-mechanics	3
<b>Total</b>		<b><u>25</u></b>

The team in Zinder is supported at Sentinelles' Head Office in Lausanne by the Programme Officer, who undertakes missions to Zinder two or three times each year. Two volunteer workers ensure that each child's individual file is kept up-to-date. In addition, the Head of the Treatment for Children programme for those children operated on in Switzerland actively collaborates with the programme of aid for children suffering from noma.



## 5. Collaborations

SENTINELLES' work in Niger in 2012 was made possible thanks to the collaboration of national and local administrative authorities, as well as different national or foreign organisms, both private and public.

- *Government of the Republic of Niger, represented by the Ministry of Planning and Community Development (protocol agreement No. 00078/2011/DONGAD), Ministry of Health, Ministry of Labour, Governorate of Zinder, Regional Directorate of Planning and Community Development, Regional Directorate of Health.*
- *Niamey Hospital. Specialist medical examinations.*
- *CURE Children's Hospital in Niamey. Accommodation, medical and surgical care during surgical missions or individual care, principally for children suffering from a harelip.*
- *Zinder Hospital. Departments of paediatrics, stomatology, medicine, radiology and the laboratory.*
- *Zinder Central Maternity Hospital. Medical examinations.*
- *MSF Switzerland in Zinder (Doctors without Borders). Taking charge of seriously undernourished children.*
- *Zinder Catholic Mission. Free dermatological consultations.*
- *Franco-Niger Cultural Centre in Zinder. Free entertainment for children staying in the Centre.*
- *Swiss Cooperation. Provision of visas for treatment of children in Switzerland. Funding for sanitation system in Reception Centre and funding for a 4x4 vehicle for awareness raising programme.*
- *Save the Children Niger. Free supply of basic medicines and permeated mosquito nets.*
- *Raptim Agency, Geneva. Travel agency offering preferential tariffs.*
- *Blue Sky Agency, Prilly/Lausanne. Travel agency offering preferential tariffs.*
- *Aviation Sans Frontières (A.S.F.), Paris. Accompanying children during their transfer for treatment in Europe.*
- *Madala, Etats-Unis. Funding for a 4x4 vehicle for social follow up in the bush.*
- *Doctors of the World, Paris. Collaboration in Professor Servant's surgical missions.*
- *Gueules Cassées, Paris. Funding of surgical missions.*
- *Terre des hommes Valais, La Maison, Massongex. Accommodation for children between operating sessions during their treatment in Switzerland.*
- *Association d'Entraide des Mutilés du Visage (AEMV), Geneva: support for the care of children transferred to Switzerland for treatment.*
- *Winds of Hope. Funding activities of training, awareness raising, prevention and detection of noma in Burkina Faso and Niger.*
- *Noma-Hilfe-Schweiz. Financial participation in noma programme in Niger : funding of emergency food aid to families.*
- *Hôpitaux. University Hospital Geneva (HUG); Children's Hospital, Lausanne; Chablais Regional Hospitals; Genolier Clinic; St Louis Hospital, Paris.*

**And all the organisms and people, including many volunteers,  
who faithfully support by their work and their donations  
Sentinelles' action with children suffering from noma.**

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