



Noma

Contact

CANCERUM ORIS NETWORK ACTION

A disease such as noma should not exist

Since WHO launched the International Action Network Against Noma in 1994, many advances have been made in understanding how oro-facial noma develops, how the gangrene spreads and how it can be prevented. Much, however, remains to be done.

Oro-facial noma, which is often referred to simply as noma, is the disease *cancrum oris*. It is a gangrene that develops in the mouth and spreads rapidly to other parts of the face. The disease is found almost exclusively in conditions of poverty, poor living conditions, poor hygiene and malnutrition. Virtually all of its victims are children.

Hundreds of thousands of small children suffer from noma. Many die and most of the others are disfigured for life. Yet although the physical consequences of noma are horrific, this is a disease that can – and should – be prevented.

The fight against noma does not need expensive wonder drugs. For those with resources, it is easy to prevent. However, research to find out just why some children develop the disease while others in the same situation do not would help to better focus preventive action. The world has often lacked the political will to tackle noma because it is a disease that affects the poorest of the poor – the people who in most places count for very little.

History shows us that the disfigurement of noma has been known for many centuries. Not too many generations ago it was widely recognized in Europe but improvements in nutrition and hygiene gradually put an end to it. It reappeared this century in nazi concentration camps during World War II but is now found chiefly in the poorer parts of some developing countries.

In a modern world on the eve of the 21st century, a disease of poverty such as noma should not exist. The faces of the children disfigured by this disease are a shameful reproach to us.

Members of the International Action Network Against Noma – whether working for governments, international agencies or nongovernmental organizations – are active both in those countries where noma takes its greatest toll and in more developed nations giving aid to those unfortunate enough to have suffered this disease.

Inside

- Noma: a vicious and deadly disease
- Preventing and treating noma
- International action programme
- Noma in Senegal
- NGO focus: Sentinelles in Niger
- Resources

Some figures

- Mainly affects children aged 0–6 years
- Possible annual incidence (sub-Saharan countries): 2–10 per 10 000
- Case mortality rate: 70–90%

Members of the network are trying to raise nutritional standards and improve hygiene in noma-affected areas. They are spreading awareness of the extent and seriousness of the disease. They are helping families to recognize early symptoms in their children and are impressing on them the urgency of seeking medical help without delay. They are training local health care workers to recognize and treat the early signs of noma, stopping the progression of the disease before it does too much damage. They are providing surgical repair for victims of noma – either locally or, for more serious cases, abroad. And they are helping noma patients who have undergone long and difficult reconstructive surgery in a foreign country to reintegrate into their homes and communities.

The aim of *Noma Contact* is to provide a link between the members of this network. Together we aim to see that noma becomes what it should be – a disease of the past and not of the present.

Mark Tsechkovski
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Director, WHO Division of Noncommunicable Diseases



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Noma **Contact**

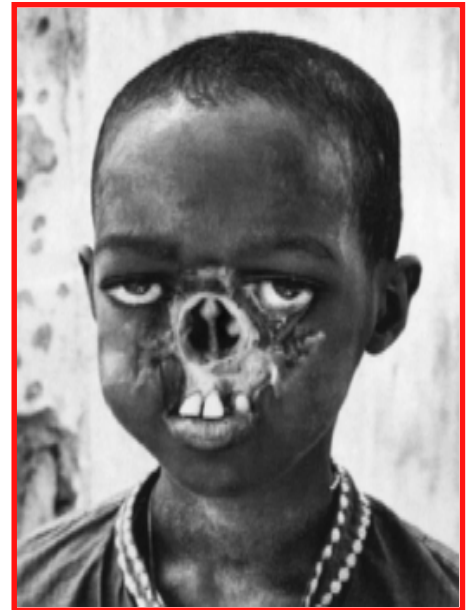
Noma: a vicious and deadly disease

Noma is found almost exclusively in malnourished children in the poorest countries. It is a vicious and deadly gangrene that affects the mouth and face. Noma causes extreme facial disfigurement and, without treatment, kills most of its victims from septicemia, pneumonia or other complications. Technically the oro-facial gangrene which is also known by its Latin name *cancrem oris* is just one form of noma, but since noma is the term commonly used for this disease it is used also here.

Exact numbers of noma sufferers do not exist. The disease is mostly found in places where health care is basic and medical records are scarce. Observations by field-workers show that noma claims more victims than used to be thought. WHO estimates that up to half a million

children are victims of noma and that over 100 000 children aged 2–6 years contract noma every year.

Virtually all cases of noma start with ulcers on the gums. From there the disease spreads to softer fleshy tissue that is in contact with the ulcers. The mouth becomes sore and cheeks or lips become tender. Next the cheeks or lips start to swell and the general condition of the child, who is usually in a lot of pain by this time, deteriorates. In just a few days the swelling becomes enormous and at the same time dark furrows appear where the flesh is decaying. In most cases the decay, although severe, is limited to one area of the face. As the gangrene destroys the flesh – and sometimes even bones – a scab forms; eventually this falls off, leaving a hole in the face, as in the photograph.



Noma eats away facial tissue, as in the case of this boy in Peru.

Once facial decomposition has occurred, four out of five children with noma will die if they do not reach hospital quickly. Those who survive carry facial disfigurement for the rest of their lives. They will never be able to eat or speak normally again. Some become social outcasts. Others suffer further physical damage if the gangrene spreads into the jawbone or even other bones in the face.

Preventing and treating noma

Most noma sufferers are under six years of age. Typically the disease affects children aged three or four years. It is generally agreed that noma results from a combination of factors. It develops in children who are malnourished and often follows an episode of infectious disease – usually measles, but also malaria, scarlet fever or chickenpox. Lack of nourishment reduces the effectiveness of the child's immune system and these diseases reduce it even further. Research into the human immunodeficiency virus (HIV) and oral diseases shows that some HIV-positive patients have microorganisms similar to

those found in children with noma. Research into this possible link is still continuing.

Noma patients are frequently deficient in vitamins, protein and iron. They also have poor oral hygiene. But although gum ulcers usually precede noma, it is not clear why noma develops in some cases but not in others.

Noma can be prevented, it can be cured, and to a certain extent its after-effects can be repaired. First of all, of course, an adequate diet for young children is the best prevention. Brushing the teeth, or at least

keeping the mouth clean, can prevent the development of gum ulcers, and especially the necrotizing gingivitis that leads to noma. And if only the gums are affected, antiseptics and antibiotics will stop the disease from progressing, though they have to be backed up with nutritional supplements such as vitamins.

Once noma has set in it develops so rapidly that little can be done to avert it. All too often medical aid is too far away or given too late to be of much use. Surgical reconstruction of the face is possible but takes a long time, mostly involves a series of operations, and is expensive. Usually it is available only in countries far away from the places where noma occurs. Prevention rather than reconstructive surgery must be the aim of health programmes.

The international action programme on noma

In November 1992 a group of organizations and individuals concerned at the damage done by noma met in Paris to discuss ways of combating the disease. Participants in that meeting, which was convened by WHO and Aide Odontologique Internationale, agreed on a plan for controlling noma. Out of that plan grew a five-point strategy that is now promoted by WHO. The strategy involves the following:

Prevention

- Setting up information and education programmes to make parents, and especially mothers, aware of the signs of noma and the urgent need to do something about it.
- Training health care workers to detect the disease and give emergency care.

Epidemiology and surveillance

- Organizing and financing research studies to find out how many children have the disease and how many more are likely to be affected (the results would provide a more effective basis for preventive action).

Etiological research

- Promoting research to find out just how noma is caused, and why it develops in some children but not in others.

Primary care

- Arranging for health services to treat patients locally.

- Making sure that the necessary anti-septics, drugs and nutritional supplements are available.

Surgery and rehabilitation

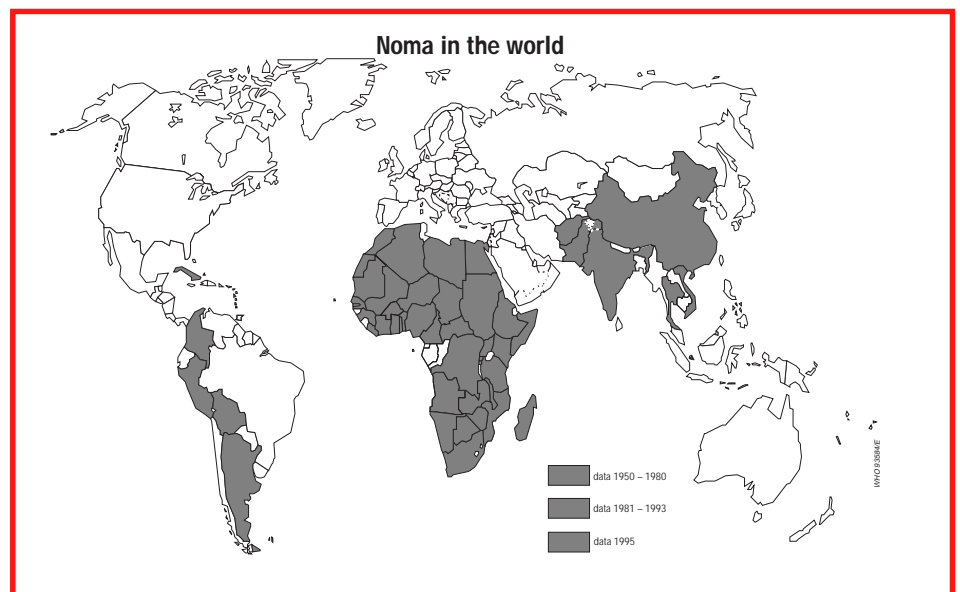
- Referring children who are severely disfigured and require complex surgical treatment; organizing transport for them; providing after-care and rehabilitation; helping to reintegrate them into society.
- Training local health care workers to assist noma sufferers.
- Setting up a specialized regional centre in West Africa for complex treatment of noma patients.

The strategy is being implemented by the International Action Network Against

rating Centres. WHO is also in contact with more than 100 individuals worldwide who are involved in the struggle against noma. WHO focuses on public health actions while the NGOs concentrate on the areas with which they are most familiar. WHO encourages all these initiatives and assists where it can, though its main investment is in the areas of prevention, etiological and epidemiological research, and primary care.

WHO urges countries to set up noma control plans, giving priority to early detection and immediate treatment. The map shows those parts of the world where noma has been reported.

The network's recent work has included training workshops in Guinea and Senegal to train health workers to recognize the disease and take steps to prevent it



Noma. This network is not a formal structure. It is a worldwide solidarity chain where each element intervenes in its area of interest and competence. It involves WHO, several nongovernmental organizations (NGOs) and four WHO Collaborating

Centres. WHO is also in contact with more than 100 individuals worldwide who are involved in the struggle against noma. WHO focuses on public health actions while the NGOs concentrate on the areas with which they are most familiar. WHO encourages all these initiatives and assists where it can, though its main investment is in the areas of prevention, etiological and epidemiological research, and primary care.

by the WHO Collaborating Centre in Lyon, France. Although this research is still at an early stage, the evidence has convincingly shown that noma is an important public health problem in many communities. Further details of the work in Senegal are described on page 5.

Collaboration with the National Institutes of Health in the USA has led to a proposal for epidemiological and also etiological research to find out what causes noma and how the disease develops. As yet scientists have not been able to identify the specific pathogen that causes the disease, and they do not know why noma is apparently more common

in some communities than in others with similar levels of poverty, malnutrition and infectious disease. Research will aim to find out if the pathogen is a normal organism that suddenly behaves more virulently in noma cases, if it is linked to immunosuppressive diseases such as herpes, if lack of any particular micronutrients in the diet play a role, and if living very close to animals has any influence. The protocol for this research is currently being prepared.

In addition, a bibliographic database on noma has been compiled with support from the WHO Collaborating Centre at Trinity College, Dublin, Republic of Ire-

land. The database contains hundreds of articles and research papers on the disease. It is currently being updated and is to be made available on the Internet.

The International Action Network Against Noma includes a network that provides surgery for seriously disfigured children. Surgeons in France, Germany, The Netherlands, Switzerland and the USA are helping to repair the damage done to young faces by noma. NGOs are helping by funding the cost of sending children overseas to have these operations and by sending teams of surgeons to Africa to operate on the less complex cases there.

Resources

Survey of orofacial mutilations and noma (leaflet WHO/ORH/EMV/93.1). Contains survey guidelines for gathering reliable data about noma. Includes a survey form. E,F.

Critères actuels d'aide au diagnostic clinique pour l'identification des manifestations oro-faciales du noma (leaflet WHO/ORH-NOMA, Oct. 1994). Describes the progress of noma from necrotizing gingivitis to the loss of tissue and other health problems. Illustrated with colour photographs. F.

International Action Network Against Noma. Background report and summary of activities, 1995. E,F.

Noma, a little-known public health problem (WHD/94.6). A brief review of the history of noma, research findings, and the main health problems it causes. E,F.

Single copies of these resources are available free of charge. Please use the order form on the back page.

Video: About noma. A forgotten disease. 1993, VHS, 15 minutes. E,F. Price: Sw.fr. 40.-/US \$36.00 (Sw.fr 28.- in developing countries). Order no. 1650078.

The video can be ordered from Distribution and Sales, World Health Organization, 1211 Geneva 27, Switzerland.

E=ENGLISH. F=FRENCH

Action must focus on deprived children

// Noma is an oral disease with a high mortality rate. It appears to be on the increase in parts of the world which are devastated by hunger and civil strife. When death is not the outcome, noma leaves the survivor mutilated for the rest of his or her life. Action must focus on nutritionally and otherwise deprived children. Against noma, WHO has developed a five-step plan of attack. This comprehensive and practical approach is based on multidisciplinary and intersectoral health interventions. **//**

**Dr Hiroshi Nakajima,
Director-General of WHO, 1994.**

The fight against noma in Senegal

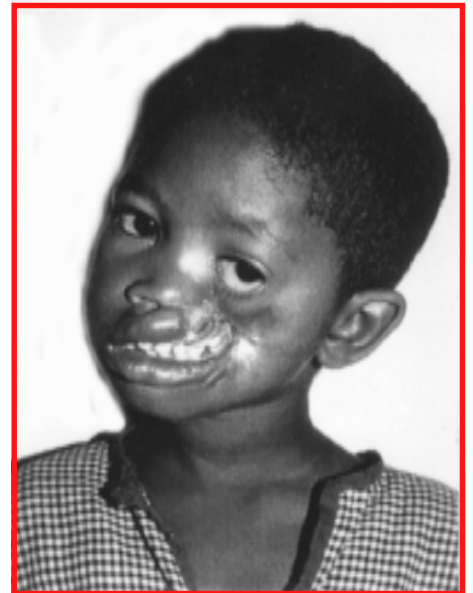
Senegal is the focus of a number of activities relating to noma. So far 35 heads of health posts in the Saint-Louis area have been trained to detect early signs of the disease and to give preventive care. This was done in cooperation with the Ministry of Health and Social Action. The health workers have also been shown how to keep records of the number and nature of cases so that a better picture can be built up of the pattern of noma throughout the country.

A regional programme of epidemiological research took place in January 1996 in the Fleuve region of Senegal to assess the prevalence and incidence of noma there. This has involved 35 health posts,

four health centres and the pediatrics department of a regional hospital.

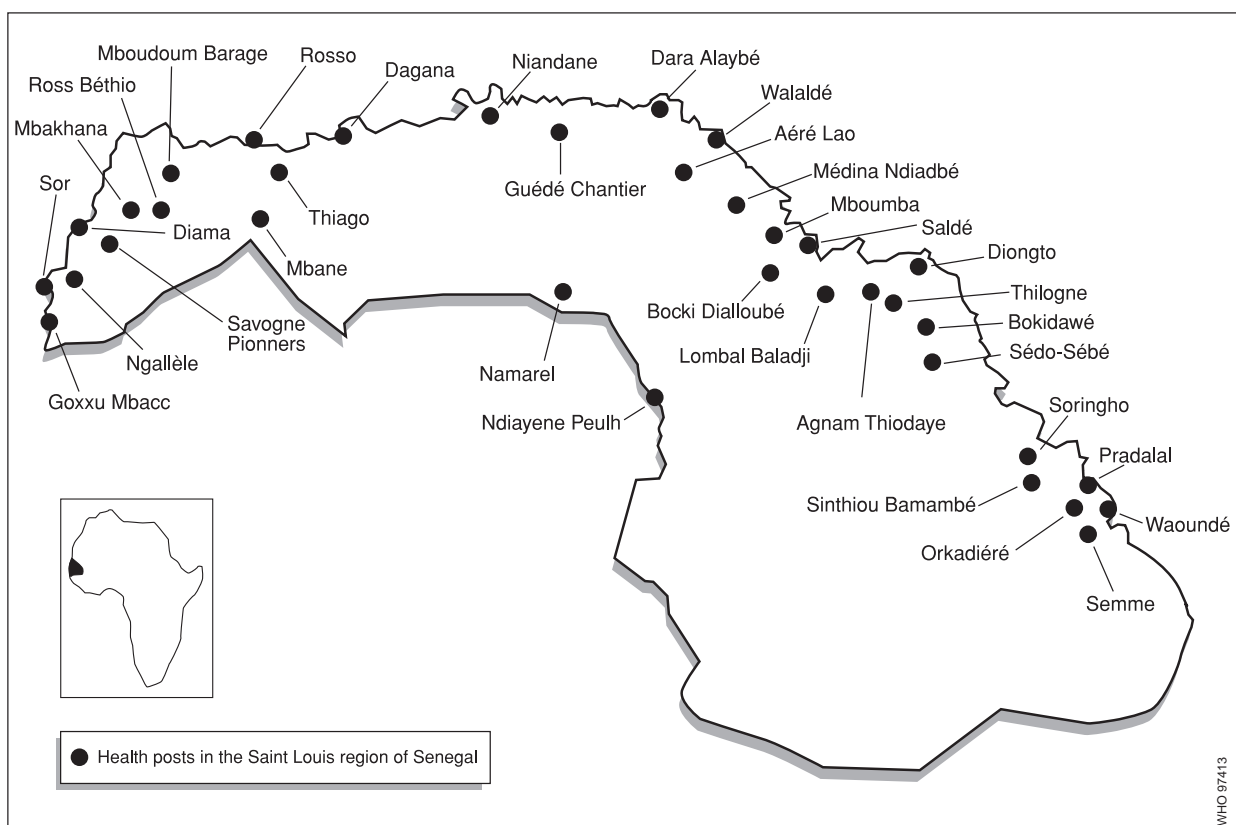
A 10-year retrospective study has been carried out of referred cases at a hospital in Dakar. This is a joint project of the University of Dakar and the University of Lyon, France. The results of the study will be available before the end of 1997.

Further research in Senegal has been trying to find out more about the cause of noma. Thus a pilot project focused on the bacteriology of acute necrotizing gingivitis in 30 malnourished children aged 1–6 years seen at the main hospital in Dakar. This has been a joint project of the University of Dakar and the University of Geneva, Switzerland.



A young noma victim in Senegal. When the damage of noma healed, scar tissue prevented this girl from eating or speaking properly.

NOMA: EPIDEMIOLOGICAL SURVEILLANCE 1996-1997



Repairing the damage of noma

A number of nongovernmental organizations and individuals are helping to repair the damage done to young victims by noma. These efforts include:

In Marseille, France, surgeons at the Faro hospital have provided plastic surgery to children severely affected by noma, chiefly from Niger, thanks to the support of the Enfants du monde ("Children of the world") organization. The French surgeons have also spent time in Niger operating on patients there and training local surgeons.

The Hilfsaktion Noma ("Relief action noma") organization in Regensburg, Germany, also works mainly in Niger. The organization sent teams of surgeons to Niger in 1996 and 1997. They operated on 45 less serious cases, while 18 children have been taken to Germany and Spain for reconstructive surgery. More than 150 patients are already registered for future surgery. The NGO has also set up a home in Tahoua, Niger, to help prepare children for treatment abroad and to help reintegrate those who return.

Surgeons from the Netherlands have been working in Nigeria where they have operated on children affected by noma. A team of surgeons visited Sokoto in the north of Nigeria for this purpose in late 1996.

In Geneva cantonal hospital in Switzerland, more than 80 children from Burkina Faso, Niger and Senegal have had facial reconstruction thanks to surgeons at the hospital and with the support of the Sentinelles ("Sentinels") organization. The Swiss surgeons, together with anaesthetists and nurses, have carried out operations on less seriously disfigured children in these three countries and have been involved in training there.

From the USA, teams of dentists travel to many parts of Africa to provide dental surgery under the auspices of Operation Smile. That organization has a surgery team that operates on noma victims and arranges treatment in the United States for the most serious cases.

Are you active against noma? Tell us what you are doing

Noma Contact is produced by WHO on behalf of the International Action Network Against Noma. It is the first of what we hope will be a series of information sheets on noma. It is, however, intended not only as an information sheet but also as a means of contact between all the organizations and individuals involved in the fight against this destructive disease.

WHO and other members of the International Action Network would like to hear

more about efforts that are being made to prevent and combat noma. *Noma Contact* can help share information about your work and your experience to encourage and assist others in their efforts. Please write to Mrs Marie-Hélène Leclercq at WHO's Noma Project (for address, see back page).

Noma Contact

Noma Contact is prepared and distributed free of charge by the staff of WHO's Noma Project. For further details, please contact: Noma Project, Division of Noncommunicable Diseases, World Health Organization, 1211 Geneva 27, Switzerland.

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NGO focus — Sentinelles in Niger

The Swiss charity Sentinelles has been working with noma sufferers in Niger since 1992. Most of the organization's work is in Zinder, in the east of the country, about 1000 km from the capital Niamey.

Apart from assisting with research into noma in cooperation with hospitals in France and Switzerland, Sentinelles has focused mainly on providing surgical aid to children disfigured by the disease. Since the end of 1992, the organization has assisted several hundred such children – mainly from around Zinder but also from other parts of the country.

Children needing attention come to the organization's reception centre in Zinder. More than 450 children spent time there in 1996. All these children were given medical assistance that included vaccines. Many had necrotizing gingivitis, which is serious enough, but others had more advanced illness. In 1996, for instance, Sentinelles gave specialized help to 180 children – 147 with noma, 32 with hare-lip and one with a tumour. Of these, 38 underwent operations when a team of surgeons visited Niger in January that year. A further 27 seriously disfigured children were taken to Europe to be operated on there. Some children received nutritional supplements and vitamins, while some were also given some basic education.

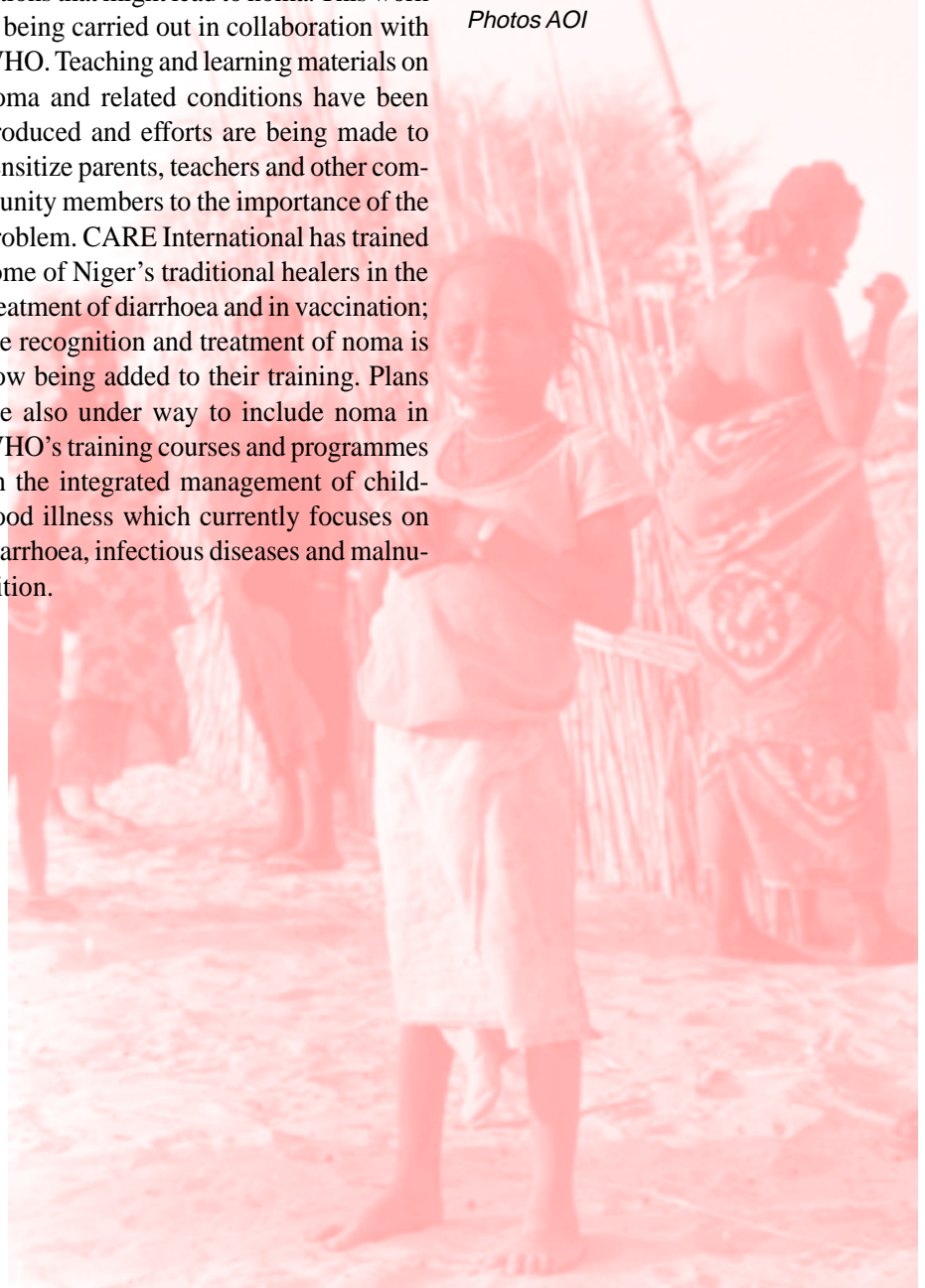


From 1993 to early 1997, Sentinelles took 73 children to Europe for surgery. Those children required an average of three operations each.

Since early 1997 Sentinelles has been carrying out more activities related to prevention and awareness of the problem. In this regard, contacts have been made with CARE International. In October 1997, Sentinelles is starting training community health workers to recognize and treat conditions that might lead to noma. This work is being carried out in collaboration with WHO. Teaching and learning materials on noma and related conditions have been produced and efforts are being made to sensitize parents, teachers and other community members to the importance of the problem. CARE International has trained some of Niger's traditional healers in the treatment of diarrhoea and in vaccination; the recognition and treatment of noma is now being added to their training. Plans are also under way to include noma in WHO's training courses and programmes on the integrated management of childhood illness which currently focuses on diarrhoea, infectious diseases and malnutrition.



Photos AOI



Institutions/Associations of the International Action Network Against Noma

- | | |
|---|---|
| Aide Odontologique Internationale, Paris, France | Providence Hospital, Southfield, MI, USA |
| Association d'Entraide aux Mutilés du Visage, Geneva, Switzerland | Rencontres Africaines, Cannes, France |
| Association Dentaire Française, Paris, France | Sentinelles, Lausanne, Switzerland |
| Cooperazione Odontologica Internazionale, Turin, Italy | Service de Santé des Armées, Marseille/Lyon, France |
| Enfants du Monde, Marseille, France | Terre des Hommes, Dakar, Senegal |
| Hilfsaktion Noma, Regensburg, Germany | Terre des Hommes, Lausanne, Switzerland |
| Hopital Cantonal de Genève, Geneva, Switzerland | University Claude Bernard, Faculty of Odontology, Lyon, France* |
| Hopital Saint-Joseph, Marseille, France | University of Copenhagen, School of Dentistry, Copenhagen, Denmark* |
| Interplast, Germany | University of Dublin, Trinity College Dental School, Republic of Ireland* |
| Médecins du Monde, Paris, France | University of Geneva, Oral Preventive Medecine, Geneva, Switzerland |
| National Institute of Dental Research, Bethesda, MD, USA* | University of Maryland, Dental School, Baltimore, MD, USA |
| Necker Children's Hospital, Microbiological Laboratory, Paris, France | |
| Nigerian Institute for Medical Research, Lagos, Nigeria | |
| Operation Smile, USA | |

* WHO Collaborating Centre

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Please send me a copy of the following resources on noma:

- Survey of orofacial mutilations and noma** (leaflet WHO/ORH/EMV/93.1)
- Critères actuels d'aide au diagnostic clinique pour l'identification des manifestations oro-faciales du noma** (leaflet WHO/ORH-NOMA, 1994) (French only)
- International Action Network Against Noma**
- Noma, a little-known public health problem** (WHD/94.6)

NAME

PROFESSION

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