Noma is a priority for the WHO African Region

This issue of the newsletter, Noma Contact, is the third of a series. However, it is the first issue published by the WHO Regional Office for Africa which, since 2001, has been responsible for the WHO Noma Programme, formerly known as the International Action Programme against Noma.

The two previous issues of Noma Contact generated immense interest worldwide both among health professionals and the general public. A large number of requests were received from all over the world for more information, showing that noma remains, more that ever, a global public health problem.

Africa is, nonetheless, by far the most affected continent. Given this alarming situation, the fight against noma has become a priority in the African Region since 1998.

In the previous issues of Noma Contact, emphasis was placed on the historical context, the obvious links between the disease and living conditions was established and the evolution of its spread geographically over time from industrialized countries to the less developed countries was traced. Thus it was shown that noma is not a tropical or even «African» disease but actually «the face of poverty».

This newsletter, targeting all those interested in the fight against noma, describes the work of the WHO Noma Programme in the African Region, the ways different African countries are dealing with this major public health problem. Further, it outlines the contribution of international partners and nongovernmental organizations, and the collaboration that exist with other WHO programmes for effective utilization of available resources as well as an integrated approach in the management of the disease.

It is our hope that the publication of Noma Contact which will henceforth be regular shall contribute, where necessary, to raise and reinforce the awareness on the importance of the fight against noma, the commitment of national and international communities to control the disease through implementation of preventive and curative actions, and the effective integration of noma within existing activities of health services and programmes.

Dr Luis Gomez Sambo
Regional Director
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### THE WORLD HEALTH ORGANIZATION ACTION AGAINST NOMA

#### Some important landmarks

<table>
<thead>
<tr>
<th>Year</th>
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• First information meeting on noma at the World Health Assembly  |
|       |  
• Adoption of the WHO Strategy against Noma  |
| 1992 |  
• Appeal of the WHO Director-General for the establishment of an international ACTION network on Noma, coordinated by the International Action Programme against Noma, comprising: foundations, research bodies, professional associations, WHO Collaborating Centres, universities, hospitals, and philanthropic bodies.  |
| 1994 |  
• According to WHO estimates, there are around 100 000 new cases every year with around 80% fatality rates in the absence of treatment (World Health Report, 1998).  |
• Noma declared a priority disease in the WHO African Region at the 48th session of the Regional Committee, Harare (Zimbabwe) (Resolution AF/RC48/R5).  |
| 1998 |  
• Donation of the Gertrude Hirzel Foundation of one million Swiss francs (around US $650,000) for WHO Noma control activities.  |
• Relaunch of the activities of the International Action Programme against Noma.  |
| 1999 |  
• Support to the establishment of the National Noma Programme in Niger.  |
| 2000 |  
• Preparation of the new global noma distribution map  |
• The Regional Consultative Committee in Burkina Faso, August 2000: Decision to transfer the International Action Programme against Noma to WHO Regional Office for Africa, as from 1st December 2000.  |
• Development of an action plan for the African Region for 2000-2002  |
• Initial donation of US $100 000 from the Winds of Hope Foundation  |
• Workshop on expanding noma research by building a research infrastructure in developing countries, jointly organized by WHO and the NIDCR (United States National Institute for Dental and Craniofacial Research) - April 2000, Washington, DC, USA.  |
• Intercountry meeting (Burkina Faso, Mali, Niger) on Noma - Niamey, from 14 to 15 August.  |
| 2001 |  
• Consultative meeting on Noma Programme Management in the WHO African Region, from 19 to 21 April, Harare (Zimbabwe).  |
| 2003 |  
• The Regional Office strengthens its technical and financial support to several countries.  |
• Expansion of the Noma Programme to several African countries: Niger, Benin, Mali, Burkina Faso, Uganda, Angola, Congo, Zambia.  |
• Participation at the intercountry meeting of IMCI focal points of French-speaking countries: integration of Noma in IMCI, Cotonou (Benin), from 2 to 6 June 2003.  |
• Organization of an intercountry workshop to prepare an action plan on noma prevention and control, Bamako (Mali), from 23 to 26 June, with participants from Angola, Benin, Burkina Faso, Mali, the Noma Children Hospital of Sokoto in Nigeria, and participants from Niger and Senegal, as well.  |
| 2004 |  
• Strengthening of collaboration with partners.  |
• Signing of a 5-year contract between the Regional Office and the Winds of Hope Foundation for noma control in 4 West African countries: Benin, Burkina Faso, Mali, Niger.  |
• Technical missions to support noma control in the following countries: Burkina Faso, Benin, Uganda, Democratic Republic of Congo, Lesotho, Zambia.  |
• Conference on Oral Health Planning in the African Region, Nairobi (Kenya), from 14 to 16 April, with a theme session on: «Towards a better Noma life without noma».  |
NOMA IN THE WORLD

Geographic distribution in 2000

The map on global distribution of noma\(^1\) does not document the scope of the disease in terms of prevalence or incidence. Rather it indicates the countries where cases of noma have been notified or reported in the literature.

The updating of the map in 2000 led to several striking observations:

- The global dimension of the disease confirmed.
- Africa remains the hardest hit continent.
- Not only is noma continuing in the developing countries, sporadic cases are also occurring in developed countries where the re-emergence of the disease seems to be linked to some determinant factors such as AIDS.
- Action regarding certain developing countries, including in Africa, where cases of noma may exist is difficult due to absence of reliable data.

It is indeed necessary to reinforce information, education and care where these are ongoing, as well as documentation of the epidemiological scope of noma in all regions where people live in similar conditions of extreme poverty.

\(^1\) The map was prepared in 2000 by the staff of the International Action Programme against Noma (World Health Organization, Geneva): Joyce Bleeker, Marie-Hélène Leclercq, Hadissa Tapsoba.
Making noma an integral part of the fight against oral diseases in Benin

In June 2003, Benin participated in the workshop to develop action plans for the prevention and control of noma, organized by the WHO Regional Office in Bamako (Mali). Following the recommendations of that workshop, a national noma project has been developed, thanks to the national health authorities, technical support of WHO and funding from the Swiss Foundation, Winds of Hope.

At Benin’s request, Dr Charlotte Faty Ndiaye, the Regional Adviser on Oral Health undertook a mission to Benin, from 26 to 31 January 2004. The aim of that mission was to strengthen the National Oral Health Programme and to facilitate the implementation of the National Noma Programme. During the mission, in addition to advocacy for the project, special emphasis was on integrated oral health approach.

On the same scale as the fight against HIV within oral health care, the noma project is an integral part of the National Programme for the Control of Oral Diseases. This programme designed to last five years (2004-2008), has been finalized by a multi-sectoral committee comprising resource persons identified from all sectors who are directly or indirectly involved in the fight against noma as well as in the community.

Administrative procedures have been initiated to appoint and establish a national noma committee. The members are chosen from all sectors involved in noma control such as health administration, pediatric, nutrition, immunization, public health, epidemiology, traditional medicine, education, NGOs, communities, women, maternal and child health.

To launch the Noma Programme, a workshop was prepared to validate the project, a televised roundtable as well as advocacy activities have been organized. Following these activities, awareness drives were conducted with appropriate information, education, and communication materials for an effective control of noma, whose core message was: «Don’t hide away children with noma, bring them out for proper treatment».

The implementation stages of the project are as follows: training, management of noma cases in the listed centres, identification of sentinel sites for epidemiological surveillance and research.

The Benin project is at its inception, collaboration among the different partners is not yet formalized at the national level, but contacts are being made with NGOs and other associations. Arrangements are far advanced with the Association of Traditional Practitioners, they often being the first port of call for children with noma.

To achieve the set objectives within the 5 years, Benin has launched an appeal to mobilize more resources.

Priority areas of the 2004-2008 Noma Plan of Action in Benin

- Prevention
- Communication
- Training of first-line health workers
- Epidemiological surveillance
- Disease Management
- Training
- Research
- Resource mobilization

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Measles vaccinations would cut noma deaths

When noma strikes, it kills nine out 10 of its young victims. The global incidence is estimated on 30 000 - 40 000, with the majority of patients in the countries directly below and besides the Sahara Desert ¹.

Poverty is the main predisposing factor for noma but the presence of a debilitating disease - such as measles, malaria, chicken pox, visceral leishmaniasis or HIV infection - can often start the gangrene off. So can the presence of a large bacterial load in the mouth, as happens with necrotizing ulcerative gingivitis.

What seems to happen when noma occurs is that impaired defence mechanisms against bacteria in the mouth fail suddenly and are overwhelmed by bacterial flora. This impairment seems to be induced by malnutrition together with an acute disease such as measles, while the bacterial load is increased by gingivitis. Once the defence fails and there is bacteriological overload: the tissues of the face are flooded with normal oral microorganisms. The gangrene spreads rapidly, often leading to sepsis and death within two weeks.

Hospital treatment cuts the risk of death, but most children with noma never reach a hospital.

Either there is no hospital near where they live, or their parents are too poor to consider such luxury. Even their deaths often go unrecorded; in their environment of extreme poverty, no health statistics are kept and noma passes unnoticed.

Among the diseases that trigger noma in a malnourished child, measles is the most important. Back at the start of the 19th century, doctors already noted the link between measles and subsequent noma - especially in poor and malnourished children.

In West Africa, where noma wrecks havoc among so many, measles is by far the leading predisposing factor.

Measles is a viral illness that can easily be prevented by immunization. Even so, measles causes about a million deaths a year - most of them in Africa. Despite the availability of an effective vaccine for decades, global measles immunization coverage in 1998 was only 72%.

In many African countries, coverage is reported to be under 50%.

In north-west Nigeria, measles immunization coverage is almost zero. It is no coincidence, then, that this area can be considered the epicentre of noma.

If you look on a map at the places where mortality due to noma is high, where vaccination against measles is low, and where poverty is extreme, there is remarkable overlap. Those areas should be the targets for future vaccination programmes against measles and other infections.


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NOMA and BURULI ULCER
Avenues for cross programme collaboration
Dr Kingsley Asiedu and Dr Hadissa Tapsoba

Noma and Buruli ulcer are poorly known diseases by the general public and the medical community. Both diseases generally occur in poor communities where medical services are poorly developed. Whereas noma affects the mouth and face, Buruli ulcer can affect any part of the body (though usually on the limbs). Most patients of both diseases are children. Noma has much higher case fatality rate than Buruli ulcer; serious disabilities result from both diseases.

Diagnosis

Diagnosis of these diseases is often made on clinical grounds. The etiologic agent in Buruli ulcer is Mycobacterium ulcerans. Buruli ulcer can be confirmed by histopathology and microbiological methods (smear, culture and PCR). In the case of noma the etiologic agent is not known.

Treatment

**Noma:** Local disinfection, appropriate antibiotics and nutritional supplementation may stop the disease from progressing to the acute gangrenous phase. Plastic and reconstructive surgery are needed for survivors with deformities.

**Buruli ulcer:** Current treatment involves surgical excision of diseased tissues, often followed by skin graft. Treatment with a combination of rifampicin and an aminoglycoside streptomycin/amikacin is promising and further research is ongoing. Like Noma, plastic and reconstructive surgery are needed for those with residual deformities.

Early physiotherapy is crucial in the management of both disease to prevent contractures.

Physical and economic rehabilitation are needed to allow those with disabilities to integrate into society.

Potential areas for collaboration

- Public education about the diseases and their consequences to encourage affected populations to seek early medical attention.
- Training of general doctors on the basic plastic and reconstructive surgery in order to develop the skills for treating both diseases and related conditions.
- Strengthening health services in affected areas particularly (surgery, anesthesia, laboratory and rehabilitation).
- Research into the pathogenesis of both disease, role of nutrition, social and economic impact etc.
What is Buruli ulcer?

Buruli ulcer was first described in 1948 in Australia. The name Buruli however comes from a county in Uganda where many cases were reported in the 1960s.

The disease often starts as a painless swelling (nodule) in the skin and without early surgical treatment, it often leads to extensive skin ulcerations. Other presentations are plaque and edematous forms.

All age groups can be affected but the disease is more frequent among children below 15 years of age. Most patients live near wetlands and close to water bodies.

The mode of transmission is not known. The causative organism, Mycobacterium ulcerans, produces a unique toxin which destroys tissue and bone and suppresses the immune system.

There are no preventive measures at this moment. Intensified education of the affected population to seek early medical attention is the only practical way to reduce the current suffering associated with the disease.

For more information on Buruli ulcer:
Communicable Diseases, CPE
World Health Organization, Geneva, Switzerland

www.who.int/gtb-buruli

Buruli Ulcer (Facial ulceration)
(© Sanarul Chauda, St. Martha Catholic Hospital, Agboyewu, Ghana)

Noma (Tissue loss)
(© Noma Children Hospital, Sokoto, Nigeria)
The “Hymne aux Enfants” Foundation in Burkina Faso

The Hymne aux Enfants Foundation (FHE), created in 1995 in Switzerland, embarked on the fight against noma in Burkina Faso, where it started medical evacuation in August 1997. Initiated in collaboration with the Ministry of Health in 1998, a noma project as part of the national oral health programme got under way on 1st May 1999.

Achievements of the noma project up to 2001

- An educational film about noma has been made
- A trainer’s guide and learner’s guide for the training of nurses
- Office equipment for the Directorate of Preventive Medicine

Missions for surgical interventions

- From 2001 to 2003, four surgical missions were organized in collaboration with the ORL unit of the Yalgado Ouédraogo National Hospital and the French Association «Enfants du Noma», which led to the treatment of 75 patients

Since 2003

- In Burkina Faso
  The FHE has developed a programme of awareness and prevention in support of the National Noma Programme. That was how some fifty educational discussions were organized in twenty-five villages in the Sissili province in 2003. Then in 2004, there was an awareness drive in Kongoussi health district: 45 villages were visited by resource persons of three local associations who had been specially trained in noma control.

- In Europe
  The FHE restructured by creating three zones of activities with a degree of autonomy in regard to decision making and finances, under the supervision of the International Foundation Board. All the activities in Burkina Faso are now under the African zone.

FHE in Ouahigouya
(Yatenga Province, northwest of Burkina Faso)

- In September 1999
  A unit was opened for noma children or those with sequellae of the disease, for example serious facial deformity. All these children suffer from social exclusion due to their condition. In these very poor communities, FHE action has also extended to cover children with heart diseases.

- In November 2003
  “Koamba Zaka”, a new national social and health facility with 40-50 bed was opened. Its inauguration on 30 January 2004 was attended by many dignitaries including the Minister of Health and the First Ladies of Burkina Faso and Mali. With a team of 13 staff, the centre regularly hosts between 25 and 30 patients and a dozen accompanying carers. The patients suffer from noma and other serious conditions (osteitis, Burkitt’s lymphoma, tumors). Eleven children have received chemotherapy since the beginning of 2004.

The centre has a pharmacy and an infirmary where patients are given the care required. Two rooms with six beds are for holding patients who need specialist attention. When that is necessary, the patients are transferred to the health facilities of Ouahigouya or Ouagadougou.

In-patients are lodged free and sleep on mats in the holding rooms designated for boys/men and girls/women. They are fed three times a day and children up to age 15 receive two additional daily snacks; blankets are provided during the cold seasons; crockery for food; and clothing as needed.
Arrangements for leisure activities exist for the young children (swings) and for the older children (football field and playground). In addition, there is a monthly theme-based programme shown daily, and individualized basic schooling provided by a teacher.

Patients come from all over the country, identified by the network that is gradually establishing: teachers, health workers, religious leaders, police commissioners, rural radio broadcasters and rural resource persons, former patients, and through media coverage and routine detection activities.

The main partners

FHE works in collaboration with: the Ministry of Health, Association Persis Burkina, Les Enfants du Noma and Sentinelles, another Swiss NGO.

The main funding sources are: Suka Foundation, Winds of Hope Foundation, SOS enfants abandonnés, Chrétiens pour le Sahel, Fraternité St Paul, Association Persis Essonne SOS.

More information on the Foundation is available at:

www.fhe-noma.org

“We are all responsible for the children in the world. Each child is unique and necessary. If one dies, it is a loss of a pearl forever. It is the loss for humanity, an emptiness that cannot be replaced by another.

The ethics of the Foundation, the guiding principle of all our actions, is to accept our fundamental responsibility towards children and enjoy it as a hymn dedicated to the children of the world, without forgetting to appreciate the moments of joy and celebration beyond the suffering, as only children know how to.”

“The Koomba Zaka Centre is first and foremost a centre for physically and psychologically mutilated patients. The disfigurement of the faces of these children and adults by the disease is unacceptable. But even more, the affected people themselves no longer want to see the averted looks, or surprise or disgust of others as a result of their condition. They do not want to frighten anyone. They refuse to surrender to the battle of life. They simply want to rediscover human dignity, a face, a smile that once again opens the door to friendship and peace with another human. The Centre seeks to enable each of them to take their place in the community, find their stolen childhood, rediscover play and laughter...share the warmth of friendship, and taste restored dignity. The door to man’s innermost being is the face...”

Ariane Vuagniaux, Resident Representative of Hymne aux Enfants Foundation

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No-Noma Federation
The international action network on noma expands

At the initiative of the *Winds of Hope* Foundation, the International Federation regrouping associations, foundations et NGOs active in the fight against noma was launched in March 2003. This Federation designed above all to serve as a framework for the exchange of information and experiences among the different actors now has 26 members.

<table>
<thead>
<tr>
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<td>Sentinelines</td>
<td>Les Cerisiers Route de Cery CH 1008 Prilly Suisse  Tel. +41 (21) 646 19 46 <a href="mailto:sentinelles@vtx.ch">sentinelles@vtx.ch</a> <a href="http://www.sentinelles.org">www.sentinelles.org</a></td>
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<tr>
<td>Winds of Hope</td>
<td>20, avenue de Florimont CH 1006 Lausanne Suisse  Tel. +41 (21) 320 77 22 <a href="mailto:info@windsofhope.org">info@windsofhope.org</a>, <a href="http://www.windsofhope.org">www.windsofhope.org</a></td>
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</table>

Further information is available at: [http://www.nonoma.org](http://www.nonoma.org)
Resources


- 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. (English, French).


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

- Additional information on the Noma Programme can be accessed in French and English at:
  http://www.afro.who.int/noma/

- Noma Contact is prepared and distributed free of charge by the Noma Programme, World Health Organization Regional Office for Africa.

Access Noma Contact online at:
  http://www.afro.who.int/noma/

Editorial Board
Dr Charlotte Faty Ndiaye
Dr Hadissa Tapsoba
Second Meeting on the Prevention and Control of Noma in the WHO African Region
Niamey, Niger, 06-08 February 2006

The Second coordination meeting on the fight against noma in the WHO African Region was convened in Niamey, Niger from 06 to 08 February 2006.

Following the workshop on the Prevention and Control of Noma organized in June 2003 (Bamako, Mali), national action plans on noma funded by the Winds of Hope Foundation were developed and implemented in Benin, Burkina Faso, Mali, and Niger since 2004.

The objectives of the Niamey meeting were:

■ To review the progress made in the implementation of national action plans
■ To identify difficulties and constraints and make recommendations
■ To elaborate the 2006 national action plans against noma

This meeting was attended by focal points of six countries in West Africa (Benin, Burkina Faso, Mali, Niger, Senegal, Togo), and representatives of Winds of Hope and WHO/AFRO.

Final Report available at: www.afro.who.int/noma/ (French only)

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

Noma Contact also aims to build bridges between organizations and individuals who are active in the fight against this destructive disease.

Tell us what you are doing, regardless of your area of work.

Noma Contact can help share your experiences, and to encourage and assist others in their efforts.

For more information, please contact:

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For more information, visit the Foundation’s website at: www.windsofhope.org