

NOMA : THE FACE OF POVERTY

When you hear its name for the first time, you don't know what it is. When you hear its description, you can't believe it. And when you see it with your own eyes, you're never the same again. Noma is a disease that not only leaves indelible scars on the face of its little victims, but also burns the memory of its effects onto the minds of those who encounter it: the shame of not knowing sooner, the horror that something like this still exists in the 21st century, the incomprehension as to why so few humanitarian associations are involved.

Because Noma isn't contagious, it's nobody's priority. Because it's directly linked to malnutrition and poor hygiene, it's seen as a problem without a solution. And yet it is a symbol. It is the symbol of the state of disparity in which our world is evolving, fractured into extravagant societies and starving populations, ultra sophisticated technologies and total destitution. It is also the symbol of our short-sightedness when we forget that humanity won't be able to advance very far by leaving three-quarters of its population behind. Sounding the alarm is not a simple gesture of naïve solidarity, but truly of addressing the problem of safety for the future of our planet.

Dr. Bertrand Piccard

President of the International NONoma Federation
President of the Winds of Hope Foundation

WORLD NOMA DAY – Thursday, May 22, 2008

IN ASSOCIATION WITH: WHO, WHO/AFRO

WITH THE COOPERATION OF: FDI WORLD DENTAL FEDERATION

ORGANIZED BY: INTERNATIONAL NO-NOMA FEDERATION

UNDER THE PATRONAGE OF: KOFI ANNAN

UNDER THE PRESIDENCY OF: BERTRAND PICCARD

VENUE: INTERNATIONAL CONFERENCE CENTER (CICG) – GENEVA

GALA DINNER - WINDS OF HOPE

WORLD NOMA DAY

OBJECTIVES OF NOMA DAY: INFORM AND PREVENT

- alert the international community of the ravages of Noma affecting children;
- increase actions to prevent Noma in the countries concerned;
- reinforce the commitment of governments to this disease;
- develop and foster partnerships between private initiatives and government authorities to improve the prevention of Noma;
- mobilize resources to fight against Noma;
- implement a policy of common actions to eventually eradicate this disease.

WHO'S COMMITMENT

In 1994, the World Health Organization declared Noma to be a public health issue.

Noma exists throughout the world, predominantly in Africa.

Since 1998, the WHO has estimated over 140,000 annual cases of Noma, with a 70% - 80% mortality rate.

Noma is a disease that mainly strikes children between the ages of 0-6.

The WHO's strategy to fight against Noma is based on prevention and early detection, immediate care, informing and educating the public, epidemiological data collection and the creation of a referral center for treating its aftereffects.

Since 2001, the WHO/AFRO has been operating a regional program to fight Noma with the primary goal of eradicating this disease in the African region, which remains the hardest hit. It entails setting up and incorporating prevention and treatment of Noma cases into national oral health programs. In recent years, WHO/AFRO has bolstered its action to develop and implement national programs to fight against Noma.

There has been a veritable surge in assistance to Member States with greater mobilization by the international community .

In May 2007, the World Health Assembly adopted a Resolution urging support for programs for the fight against Noma in countries affected by the disease.

FDI'S COOPERATION

The FDI World Dental Federation is the independent, authoritative voice of the dental profession with over 130 association members from more than 125 countries, representing nearly one million dental surgeons in the world.

The FDI supports the WHO's plan of action for worldwide oral health and its goal of raising awareness among political leaders about the link between oral health and systemic health, educating the public on oral health issues in underprivileged countries, deploying adapted strategies and developing private and public partnerships.

The FDI offers a single network of members, partners and public health representatives and works in collaboration with the WHO to publish scientific and informative reference documents.

BERTRAND PICCARD'S PRESIDENCY

In the wake of his successful round-the-world tour in a balloon, humanitarian commitment has taken a foremost role in the life of psychiatrist-explorer Bertrand Piccard. As a United Nations Goodwill Ambassador, he is involved in programs to fight against poverty. With the Winds of Hope foundation co-created with Brian Jones, he fights Noma through actions in the field that currently benefit six African countries. He also uses his conferences and political meetings to raise funds and spread information on the existence of this terrible scourge.



Dr. JT Barnard Executive Director of FDI, Dr. Bertrand Piccard President of Winds of Hope Foundation, Dr. Luis Sambo, Director of WHO's Regional office for Africa

KOFI ANNAN'S PATRONAGE

In the context of his collaboration with the United Nations, Bertrand Piccard has had several opportunities to meet Kofi Annan and discuss the state of distress of certain regions of our world and in particular, poverty-related diseases, such as Noma. We naturally thought of him to patronize the first-ever World Noma Day.

EVENT PROGRAM

INFORMATION SESSIONS

Actions taken to fight against Noma break down barriers among the various medical disciplines and global communities, and bring together established institutions and social groups. They also create links between curative care and public health, and bridge the gap between scientific knowledge and traditional beliefs.

Emphasis will be placed on an overall and informative approach by presenting the disease and its social, medical and humanitarian context. These sessions will act as a platform of communication through conferences for the general public, personal testimonies and visual presentations.

This event will be an excellent opportunity for humanitarian organizations to present their work undertaken in the field, share practical experiences and develop exchanges to create synergies. It will also help to establish a better definition of NGO support in countries and identify the elements of a joint plan of action among NGOs and national programs.

Platform of communication on the themes of:

- Prevention
- Medical treatment
- Surgical treatment
- Research
- Epidemiology and risk factors
- Social reintegration
- Tradition, culture and Noma

Community village with information stands held by the associations affiliated with the NoNoma Federation by topic, such as information and prevention, surgical treatment, follow-up and scientific research, with photo boards, activities and continuous play film broadcasts, etc.

General public conferences and testimonies of a young man and woman on their successful reintegration and being able to speak of their experiences to an audience.

SCIENTIFIC CONFERENCES

Renowned lecturers, world-recognized scientists, experienced surgeons and WHO representatives will be invited to discuss specific topics:

- epidemiology of Noma and risk factors
- malnutrition in developing countries and its implications on Noma
- current state of research and new hypotheses
- treatment of "acute Noma" cases
- on site surgical treatment
- humanitarian surgical treatment
- repercussions of Noma

YOUTH FORUM:

Events will be organized in schools prior to Noma Day to distribute information kits and mobilize children for this cause (organizing drawing and poem contests about Noma, having them collect funds in money boxes resembling African masks, etc.)

PRESS CONFERENCE

A large scale information campaign must be led to lobby for the eradication of Noma by informing and mobilizing media to raise awareness within the international community and public opinion on the existence and reality of Noma. As part of World Noma Day, a press conference will be held with the presence and support of Bertrand Piccard.

AGENDA (subject to change)

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| 8:30 a.m. | Welcome | |
| 9:00 a.m. - 9:30 a.m. | Official opening of World Noma Day – Bertrand Piccard
Officials from countries, WHO, FDI and press are invited to attend | |
| 9:30 a.m. -12:30 a.m.
in parallel | Scientific Conferences | Salon 2 |
| 9:30 a.m.-16:00 p.m. | “Village” | |
| 9:30 a.m.-10:30 a.m. | Inauguration of the Village by B. Piccard, officials and press | |
| <i>12:30 p.m. - 13:30 p.m. Lunch – self-service buffet– (tickets can be bought at reception)</i> | | |
| 13:30 p.m.-16:00 p.m.
in parallel | Scientific conferences | Salon 2 |
| 1:30 p.m. - 4:00 p.m. | “Village”
Informational sessions
Youth Forum | Room 23 |
| 4:00 p.m. - 5:00 p.m. | Press conference and closing speech - Bertrand Piccard | |
| 8:00 p.m. - | Gala Dinner | - organized by the Winds of Hope Foundation |

THE DISEASE

Noma, derived from the Greek “nomein” meaning “to devour”, is a devastating necrosis that develops in the mouth and atrociously ravages the face. It destroys both the soft and bone tissues of the face and mostly affects young children between the ages of two and six. It can strike any community that suffers from extreme poverty and malnutrition, and is thus often called **“the face of poverty”**. Even those who are familiar with Noma cannot help but be shocked and moved by the sight of children who have been so horribly disfigured.

Several factors foster the breeding ground for Noma: lack of hygiene, particularly oral hygiene, malnutrition which lowers immune defenses, the effects of infectious diseases such as measles, or malaria and HIV/AIDS which weaken the system. The situation is aggravated by precarious standards of living that characterize extremely poor countries such as difficult access to health care, proximity to livestock and ignorance of the family and the community in seeing it as a curse, unaware that Noma is curable. Those who survive Noma are thus left to suffer from discrimination and stigmatization from their community.

Historical facts: Noma was already known in Ancient times to doctors such as Hippocrates and Gallien. In 18th and 19th century Europe, numerous texts spoke of this disease. Cases of Noma were also observed in the United States and Europe until 1901. In the 20th century with the development of hygiene, Noma disappeared from industrialized countries, with the exception of cases described in Nazi concentration camps in Auschwitz and Belsen.

Noma today: Today, Noma, endemic in numerous countries in Africa, Asia and South America, has reached public health issue proportions especially in certain populations of the Sahelian region. The mortality rate is high (+50%), and those who survive are forced to live with permanent disfiguration and the inability to eat or breathe normally. Like with leprosy, victims are often rejected by their own communities.

According to the results of certain WHO studies:

- **Over 100,000 children suffer from Noma every year.** Victims are almost always children between the ages of two and six;
- **Currently, there are 500,000 Noma survivors in the world.**
- Without treatment, Noma is fatal in 70-90% of cases, and an extremely high number of deaths still do occur;
- The poorest countries in Africa, Asia and South America are affected but the African continent is the hardest hit, accounting for 80% of cases;
- Today, Noma, endemic in numerous African countries, has reached public health issue proportions, especially in certain populations of the Sahelian region, also referred to by some as the “center of Noma”;
- Cases of Noma and most other diseases related to oral hygiene may be on the rise in Africa, due to a general deterioration of living standards: malnutrition, poor hygiene, HIV/AIDS, conflicts, corruption, etc.

To date, activities in the fight against Noma have been implemented mainly in Africa in the following countries: Angola, Benin, Burkina Faso, Lesotho, Madagascar, Mali, Niger, Nigeria, Uganda, Democratic Republic of Congo (DRC), Senegal, Togo, Zambia and Zimbabwe.

At present, it has not been possible to focus on Asia and Latin American due to insufficient funds.

THE INTERNATIONAL NO-NOMA FEDERATION www.noNoma.org

For several years, the Winds of Hope Foundation has been organizing round tables bringing together most of the organizations that fight against Noma, to create synergies among them and reinforce their respective work.

On March 20, 2003, the **International No-Noma Federation** was created at the initiative of the Foundation. Presided by and under the auspices of Winds of Hope, its purpose is to consolidate the efforts of all the players in the field dedicated to this fight, while emphasizing the exchange of information and collaboration.

Its primary mission is to:

- Present common actions and a single representative voice to international and local health authorities;
- Inform the public and mass media of the need to fight against Noma;
- Offer its members a platform of communication using new technologies to improve their operations in the areas of prevention, detection, research and medical and surgical treatment.

Today, **about thirty NGOs, associations and foundations** comprise the Federation. They fight against Noma by undertaking actions in:

- **Etiological research**
- **Epidemiological surveillance**
- **Prevention with awareness campaigns in villages**
- **The fight against malnutrition.**
- **Training of health care workers and traditional practitioners**
- **Early detection**
- **Primary health care**
- **Reconstructive surgery and rehabilitation**

The Federation partners

- OMS/Afro
- FDI (World Dental Federation)

Zimbabwe
France

Federation Members

- A Better Life Foundation
- AEMV – Association d'Entraide des Mutilés du Visage
- Antenna Technology
- Association Chariot Magique
- Au Fil de la Vie
- Aviation sans Frontières
- AWD-Stiftung Kinderhilfe
- The Dutch Noma Foundation
- Enfants du Monde
- Enfants du Noma
- Facing Africa – Noma
- Fondation Campaner
- Fondation Hirzel
- Gesnoma
- The Society for Implantology and Tissue Integrated Prosthesis (GIGIP)
- Hilfsaktion « Noma » e.V.
- Hymne aux Enfants
- Hymne aux Enfants- Belgique
- Association Idées'Elles
- La Voix du Paysan
- Mama Project Inc.
- Médecins du Monde
- Non au Noma en RDC
- Noma Hilfe Rheinbach e.V.
- Noma-Hilfe Schweiz
- Physionoma
- Santé et Développement
- Sentinelles
- Winds of Hope

Switzerland
Switzerland
Switzerland
Switzerland
France/Mali
France
Germany
The Netherlands
France
France
England
Spain
Switzerland
Switzerland
Austria
Germany
Burkina Faso
Belgium
Switzerland
Burkina Faso
U.S.A.
France
Dem. Rep. of Congo
Germany
Switzerland
France
France
Switzerland
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