

**Present :**

- Presidency: Winds of Hope (WoH).
- Active Members (23): A Better Life Foundation, AEMV, Antenna Technology, Au fil de la vie, Aviation sans frontières, Bilifou-Bilifou, Enfants du Noma, Ensemble pour Eux, Gesnoma, Hilfsaktion Noma, Hymne aux Enfants, Label Vert, La Voix du Paysan, La Maison de Fati, MAMA Project, Noma-Hilfe-Schweiz, Non au Noma en RDC, Persis Burkina, Persis Valais, PhysioNoma, Project Harar, Sentinelles, Winds of Hope.
- Partner Member (1): FDI.
- Associate Member (1): Centre Nopoko

**Guests**

Médecins Sans Frontières (MSF), Mercy Ships, Augustin Koara (Maison de Fati), Marianne Wanstall (interpreter).

**Apologies**

AWD Stiftung Kinderhilfe, Dutch Noma Foundation, Facing Africa, Idées'Elles, Peter Ustinov Stiftung, Prométhée, WHO/Afro.

**Absent**

Enfants du Monde, Hirzel Fondation, GIGIP.

**Friday 28 September**

The Round Table was declared open at 14h30 by the presidency with the following agenda:

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## 1. Adoption of Minutes

Philippe Rathle, WoH, reminded everyone that these Minutes and their translation represent a lot of work but are really useful for the amount of information they contain and the overview they give of the fight against noma. They provide a rich account of the activities of the members of the Federation.

- Minutes of the 10th Round Table 2011

As the Minutes of the 2011 Round Table had been sent out very late to the members, it was decided to postpone their adoption until this Round Table so as to allow members to make any remarks and comments they might have.

Philippe gave a brief reminder of the most important elements that had marked the meeting:

1. Relaunch by the coordinator of the WHO Office for Africa of the WHO Regional Program combatting noma, controlled and financed by WoH.
2. Presentation of the National Programme against noma of Niger by the Coordinator of the Ministry of Health.
3. Presentations on seven programs carried out thanks to financing from Noma Day.
4. Presentations by two new members and five other members of the Federation.
5. Study on the social impact of noma by Gesnoma.
6. Study on the link between severe malnutrition in a population and childhood diseases, particularly noma, by Jean Ziegler to the Council of Human Rights

Philippe opened the floor for discussion on the Minutes of the 2011 RT.

As nobody asked for the floor, he declared the Minutes of the 10th Round Table, adopted.

- Minutes of the 11th Round Table 2012

All members having received the Minutes of the 2012 RT in good time, Philippe made a brief summary of the most important points raised at that meeting:

1. Persis' maxillofacial surgery mission to Ouahigouya in January 2012 - showed effective coordination and synergy within the Federation.
2. Sentinelles' 10 years of exemplary support for Zeinabou.
3. Achievements and prospects for the cooperation agreement between WHO and WoH on the noma programme and specification of activities for Community Health Workers.
4. Situation report on Gesnoma's completed and ongoing studies and decision to establish a working group to develop a simple, standard definition for each of the stages of noma.
5. Presentations by three members of the Federation, as well as audio-visual educational materials produced by the nurse at a reception center in Ouagadougou.
6. Discussions on the purpose and content of the nonoma.org website requested by members.
7. Consequences of the adoption of the resolution by the Council of Human Rights.
8. Exchange of information and experience on the security situation in Africa.

Philippe opened the floor for discussion on the Minutes of the 2012 RT.

As nobody asked for the floor, he declared the Minutes of the 11th Round Table adopted.

## 2. WHO's regional program against noma

Philippe informed members of the absence of Dr. Benoit Varenne, due to disagreements on cooperation between WHO and WoH. Indeed, the Foundation had decided at the beginning of the week to suspend, not terminate, the renewal of the contract between the two organizations due at the end of the year. It had been forced to make this decision for reasons related to lack of financial transparency, non-compliance with the contract, unfair interpretations thereof, and decisions taken unilaterally by the WHO without prior consultation, despite WoH having invested more than CHF 2 million over a period of nearly 12 years.

The objective was to administer an electric shock, and that seemed already to have had an impact: Dr Charlotte Faty Ndiaye had contacted Philippe, Benoit Varenne had had to cancel his trip at the last minute, and meetings were scheduled to take place at the highest level in November in Geneva.

Bertrand Piccard highlighted the contrast between the way voluntary humanitarian associations operate and the governance of large government institutions. But he gave a reminder that WoH does not support the WHO but rather is associated with it to make its campaigns more sustainable by involving the Ministries of Health in the countries supported. WoH supports national training and prevention programs. It asks the WHO for administrative and logistical assistance to monitor the smooth running and funding of the planned activities. The training of health workers is a long-term working goal that complements the short-term work conducted by the member associations of the Federation.

## 3. National program fighting noma in Benin

Philippe introduced Dr. Armande Gandjeto, a doctor specialising in oral medicine and public health as well as a health communicator, who is the noma coordinator and focal point in Oral Health at the Ministry of Health in Benin. He invited her to present their anti-noma activities.

Armande first gave some important information about the Beninese context:

- more than 8 million inhabitants, 33.3% live below the poverty line
- a GDP of USD 1,500 per capita in 2008 and economic growth of 2.7% per year
- political stability since 1990

Armande then gave details of the main health facilities:

- National University Hospital Centre (CNHU), Cotonou
- 5 Departmental Hospital Centres (CHD)
- 34 regional hospitals (HZ)
- 80 community health centers (CSC)
- 359 District Health Centres (CSA)
- various denominational and private institutions

She also reminded members that Benin has only 0.86 dentists per 100,000 inhabitants. In 2012, there were 60 dentists for the whole country, 12 in the public sector, 10 in the religious sector and 38 in the private sector. There is a lack of dental infrastructure at the peripheral level to support those needing treatment, and poor geographical and financial access to dental care.

Four NGOs are partners in oral health and the fight against noma in Benin: Enfants du Noma, Smile Train Italia Onlus, Joseph The Worker and Non-Derabou-Dokpikinou

Armande then provided an overview of anti-noma activities from 2003 to 2012:

- Component 1: Trainers are monitored every six months.
  - training and retraining of health workers: 920
  - training and retraining of dentists: 50
  - training and retraining of doctors coordinating health zones and health center chief medical officers: 153
  - paramedic training (Nurses, midwives, social workers): 920
  - training of community volunteers: 300
  - training of women's groups: 66
  - training of traditional healers: 50
- Component 2: Early detection of cases by community volunteers who guide patients towards health facilities, and organization of field trips for detection and medical care.
  - 7 cases of noma detected in the ENT department of the CNHU 1979-1988
  - 26 cases of noma identified and treated by Mercy Ships in 1997, 2000 and 2001
  - 6 noma cases detected during screening field trips from 1995 to 1998
- Component 3: awareness-raising and social mobilisation.
  - awareness-raising in schools on the prevention of noma: 50 schools
  - awareness-raising with mothers of children aged 0-6 years: over 3,000 mothers
  - production of widely-broadcast TV and radio awareness-raising spots
  - media campaigns on community radio, press and television
- Component 4: Development of training and educational materials: flipcharts, posters, pamphlets, awareness-raising booklets, projectors, laptops, flip charts
- Component 5: epidemiological surveillance
  - National retrospective survey on noma in 2007, revealing 57 cases: 1998-1999: 18 cases; 2000-2007; 39 cases; 2 deaths recorded during the survey, 72% of cases detected more than 15 years ago (sequelae)
  - Sentinelles monitoring points (dentists)
  - Notification of cases to the IDSR (Integrated Disease Surveillance Response system)
- Component 6: Programme coordination and follow-up.

The major problems in the field are:

- diagnostic difficulties due to ignorance about the clinical indications
- difficulties in management of detected cases because of family poverty
- lack of government financial resources for the care of cases detected

Successes and progress made include:

- beginning of a change of behavior in the community: noma is no longer considered a curse a demonic disease
- populations are responding favorably to awareness-raising and asking us for further information
- a Benin stylist, Pepita D, organized a fashion show on 2 July 2009 for the benefit of noma-affected children and raised 21 million CFA francs (~ 40'000 CHF)

Yvan Muriset of Sentinelles welcomed the commitment and involvement of Armande, which were a pleasure to behold. Following a question from Dr Pierre Seguin of Enfants du Noma, Armande explained that the recent detection of fresh noma cases showed that training and education were bearing fruit.



#### 4. Mercy Ships, the hospital ship

Philippe welcomed the cooperation initiated between Mercy Ships and WoH in order to explore possible collaborations in the fight against noma. He also wanted to convince Mercy Ships that it should join the Federation. The Director for Switzerland, René Lehmann, retained by other commitments, was represented by Dr. Peter Linz, Chief International Medical Officer for Mercy Ships, who presented their international humanitarian organization.

Peter began by giving us some information about Mercy Ships and the largest non-governmental hospital ship in the world:

- Established in 1978
- Over a billion dollars worth of health care services provided free of charge
- 61,000 operations carried out
- 540,000 patients treated
- 29,500 local health professionals trained
- More than 1,000 volunteers per year
- Present in West Africa since 1990

The Africa Mercy is a surgical hospital ship specialising in the fields of maxillofacial, plastic, orthopedic, general, ophthalmic and dental surgery. It provides direct healthcare, raises awareness about health, and trains local medical personnel. The ship visits 17 coastal countries in West Africa from Senegal in the north to Congo in the south. On average, it spends 10 months at anchor off each country visited.

The majority of the population in most of these countries lives on less than 2 dollars a day.

Peter then introduced a film on his humanitarian organisation.

" In West Africa, poverty and limited access to medical care are major killers. With only one doctor for every 20,000 residents, people with serious diseases do not have access to the treatment they so greatly need. Those who suffer from these physical illnesses often also have to bear the heavy and tragic burden of loneliness. But practical help is on the way in the shape of a big white hospital ship with a crew of 400 volunteers from more than 30 countries. "

" Since 1978 , Mercy Ships, an international humanitarian organization has been providing medical care to the poorest nations. Using a ship as a platform for its hospital, Mercy Ships can take advanced equipment, such as a scanner or a medical laboratory to countries that rarely have access to this kind of service. All members of the crew, from the captain to the cooks, the sailors to the medical teams, work together to put six operating theatres on board into operation, as well as ophthalmic and dental clinics ashore. "



"The selection of patients for a free operation begins with a day of medical screening. Thousands of Africans are willing to wait several hours in the sun just to be seen by physicians from Mercy Ships. Once it is determined that a patient can be treated, he receives an appointment card for treatment on the ship. For many, this moment already represents a dream come true."

For hope to be credible in the future, it must be tangible in the present. In order that hope may one day germinate, it must be felt in the present moment. And I think that's what happens when people undergo an operation on our ship. Hope becomes palpable. People are healed. They return to their villages and the villagers see that they have got better and something has happened. This gives them a reason to hope for a better future because something concrete has happened in the present." (Dr. Gary Parker, Chief Medical Officer of the vessel Africa Mercy)

"Whilst the operations that radically transform lives are carried out on board the ship, teams also provide assistance ashore. For example, the ophthalmological team conducts eye examinations and treatments and distributes glasses. The dental team from Mercy Ships sees hundreds of patients every day in an on-shore clinic. Hygienists also visit schools to teach children the importance of healthy teeth, and to distribute toothbrushes. "

"Another important aspect of the work of Mercy Ships is the strengthening of local capabilities, improving skills in the country so as to ensure that local people have better access to healthcare. Local surgeons, ophthalmologists and dentists are trained by teams from Mercy Ships. These doctors can then continue to bring hope and treatment to their own community even after the ship has left."

"We cannot change the whole world, but we can radically change the life of one person and then another, and then the next ...and yet another. " (Dr. Gary Parker).

Peter reported that the hospital ship was currently off Congo, with the families of 33 volunteers living on board, with a school for their children.

To a question from Sylvie Pialoux of Au fil de la vie, Peter replied that funding came from donors, foundations, and Christian churches but not from governments. The costs are reduced because the staff are volunteers and pay their own expenses.

Adama Sougouri of La Voix du Paysan, asked how non-coastal countries could also benefit from such a care package. Peter replied that, in the context of the cooperation currently under discussion between Mercy Ships and WoH, a child noma sufferer could be sent to them in the port where they were anchored and receive surgical treatment.

To a question from Dr Denise Baratti-Mayer of Gesnoma, Peter replied that the surgeons come from North America, Europe and Australia and are selected on the basis of their active and regular practice in their respective countries.

**5. Collaboration between Médecins Sans Frontières, Sentinelles and Winds of Hope at Zinder**

Marie Renaud, Sentinelles' responsible person in Niger, explained how collaboration had intensified between MSF and Sentinelles.

Following the meeting initiated by Jean Ziegler in June 2011 between MSF and WoH, Sentinelles had joined the subsequent discussions in March 2012 with the idea of integrating the early detection of noma into the infant therapeutic feeding centers (*CRENI in French*) run by MSF. This idea was implemented with the drafting of a protocol for the prevention, detection and management of noma, which was being tested in a pilot project at Zinder. Indeed, there had already existed a relationship between the TFC run by MSF and the Sentinelles reception center, based on exchange of information about the malnutrition situation.

The purpose of this protocol is to integrate screening for symptoms of noma into TFC procedures, so as to identify cases earlier and to facilitate their treatment. The protocol therefore includes a definition of noma; risk factors; criteria for establishing a diagnosis; a description of the stages of the disease; and treatments at each stage as well as preventive measures. Written by Dr Marie-Claire Bottineau, it is in the final stages of proofreading by MSF, Sentinelles, Gesnoma and WoH.

This protocol for the prevention and detection of noma will allow MSF to have a technical basis for their teams in the field automatically to open the mouth of every malnourished child they encounter. MSF will therefore include it in their procedures for the TFC at Zinder, and plans to apply it also at their center in Magaria, and finally to extend it to all countries affected by malnutrition where they are present.

This protocol improves collaboration in the field and support for patients. It also enables the training of nursing staff and creates a basis for partnership with those hospitals or agencies that will take over the TFC in the future. Indeed, for reasons related to the security situation, MSF decided to leave Zinder at the end of 2013 and withdraw to Magaria where they already have a center. They will return to Zinder during peak periods.

MSF is exploring the possibility of including noma prevention and early detection campaigns within their immunization and awareness-raising campaigns at the TFCs, for families and children who come to be treated for malnutrition. Also under consideration is a program to train surgical mission teams to operate on children with noma in areas where NGOs are not present.

Marie concluded by confirming that the situation is complicated in Niger, a country where health needs are so huge, but the security environment is deteriorating.

Dr. Michel Quere of Médecins Sans Frontières, confirmed that the need was very great, with 500 hospitalizations and 150,000 consultations for children under age 5 at Zinder and Magaria. Early detection by checking open mouths is a great opportunity for MSF to contain the increasing number of noma cases. The security issue poses great challenges for the availability of medical personnel.

## 6. Increase in noma cases in Niger, Sentinelles

Yvan Muriset, Sentinelles, reported first that in the Zinder region, one of the world's poorest, three times more children aged 8 to 10 had been discovered in the acute phase of noma.

Marie confirmed this, giving these figures:

- Up to October 2012, Zinder detected between 0 and 5 cases per month
- Since October 2012, 8 to 10 new cases per month are being discovered. There were 83 new cases in the previous 12 months and 59 cases from January to August 2013.

Of these 59 new cases of noma:

- The majority were born in 2008 (15) 2009 (15) and 2010 (15).
- The distribution is roughly equal between girls and boys (29 and 27 respectively).
- 4 were at the sequelae stage, 3 of whom were born before 2000
- 8 were at an advanced stage of tissue loss
- 47 were in the acute phase (swelling of the cheek, characteristic odor and bone damage)

This increase constitutes a major burden for Sentinelles.

Years of birth of newly detected cases



The three year-groups born in 2008, 2009 and 2010 correspond quite significantly to the times of recurring famines in Niger in the years 2005, 2009, 2010 and 2012 which is the first and foremost explanation for the upsurge in cases of noma. The increased number of cases discovered is explained also more generally as a consequence of the awareness-raising carried out in the field, which resulted in cases being detected, but also in word of mouth transmission of information. Five children suffering from noma were discovered in 2013 during outreach sessions. Finally, the precarious security situation prevailing in the country most likely also played a role in this development.

The Outreach team in Zinder consists of a facilitator, a driver and a manager who travel around the different regions of Niger. The specific objectives are:

- Raising awareness about Noma as a disease;
- Early detection of the disease and reflex of resorting rapidly to professional medical care;
- Promotion of oral hygiene and cleanliness in households;
- Promotion of nutritional education;
- Immunization of small children

The aim is to sensitize directly all members of a village or neighborhood as well as its traditional and village authorities: village chiefs, traditional healers, midwives, imams, teachers and marabouts.

They are also shown a film shot in August 2005 by Alexandre Nasarion, with a soundtrack in Hausa and catering for the local population. It combines scenes from everyday life and interviews with health workers or medical personnel. This awareness-raising gives us an opportunity to organize a screening session with children, and above all gives rise to the word-of-mouth communication which is so effective in Africa.

The team then goes to health centers in the affected regions and distributes the posters made available through the national programme for combating noma. Finally, it organizes exchanges with local hospitals and NGOs to discuss the disease and its management.

Gingivitis consultations at the Zinder reception center, which is open 24h/24, are free. When acute necrotizing gingivitis (ANG) cases are detected, they are cared for and remain at the center for a few weeks, the time needed to teach oral hygiene to the mother and give nutritional advice.

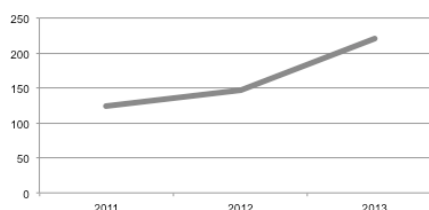
One of the direct consequences of awareness-raising is an increased number of ANG case consultations at the center.

From January to July, the statistics are as follows:

- 2013: 220 consultations
- 2012: 146
- 2011: 124

Gingivitis consultations at the Center

Consultations gingivites au centre



The acute stages of ANG will not lead to noma sequelae if the patients are treated and monitored. But monitoring of these children is costly in the long term, in economic and social terms as well as for health and schooling. In 2013 to date, 987 cases were treated in total and 357 children and their families are being monitored. With so many children to monitor and so many miles to cover, monitoring patients in the bush becomes difficult, especially given the security problems.

Marie concluded by referring to the story of Sabiou, born in 2007 and discovered in July 2012 with appallingly severe sequelae. According to sub-Saharan custom, the firstborn belongs to his grandparents and his parents should not pay any attention to him or give him affection. This boy who was monitored by Sentinelles was referred by the head of the Integrated Health Center at Ourafan, thanks to an awareness-raising session.

Dr. Denise Baratti-Mayer of Gesnoma noted that the number of cases for 2012 alone corresponded to the number of cases identified during her 5 year study. Dr. Pierre Seguin noted that in this past year, Enfants du Noma had operated on 80% more cases of noma than the previous year: 26 cases in 2011-12 and 44 cases in 2012-13. Yvan added that the increase also relates to cases of cleft lip with more than 100 children the previous month in the Sentinelles center.

Bertrand asked about the existence of security threats in Zinder. Marie replied that local authorities had suggested that Westerners should leave the area, following an attack carried out not far away. Yvan stated that their local delegate, Nathalie, and a Swiss woman heading a small NGO are the only white people living there, but they never leave the town.



**7. Publication on risk factors for noma, Gesnoma**

Dr. Denise Baratti-Mayer commented on the publication on July 5, 2013 in Lancet Global Health (Vol.1, Issue 2) of a prospective, matched case-control study, which was conducted by Gesnoma (Geneva Study Group on Noma) over a period of 6 years in Niger. The article is available "on-line" at: [http://dx.doi.org/10.1016/S2214-109X\(13\)70015-9](http://dx.doi.org/10.1016/S2214-109X(13)70015-9)

This study, which had already been presented to the Federation, involved children under 12 years of age in Niger, monitored between August 2001 and October 2006. Four controls were "matched" by age and village/case. Epidemiological, clinical and microbiological data were collected.

The key epidemiological findings, based on 82 cases and 327 controls are as follows:

- Average age: 3.7 years - the same proportion of girls and boys
- Associated risk factors:
  - Severe malnutrition
  - High number of previous pregnancies
  - Fever, diarrhea or respiratory illness within 3 the months preceding the noma
  - Absence of chickens

The main microbiological results are as follows:

- No link with the Herpes virus type and not significantly associated with measles
- Prevalence of particular bacterial species in acute noma lesions (*Atopobium* spp., *Prevotella intermedia*, *Peptostreptococcus* spp., *Streptococcus pyogenes*, *Streptococcus anginosus*)
- Classical periodontal bacteria (*Capnocytophaga* spp., *Porphyromonas* spp. *Fusobacteriales*, Act. A.) more present in the control group children

The main clinical results are as follows:

- Importance of malnutrition
- Importance of frequent, closely-spaced pregnancies
- No specific pathogen - decrease in bacterial diversity
- Importance of ANG, which is probably the starting point of noma

This publication led to a series of rather loosely-worded articles in the Swiss press (Tribune de Genève, Le Matin, 20 Minutes, etc..). Denise stated that no journalist had contacted the signatories of the press release and that articles had been published with titles such as "The causes of noma finally discovered." She added that the day before a new entry had appeared in the PLOS Medicine Community Blog dealing with neglected diseases. Philippe, on the other hand, indicated that he had been contacted twice about this subject.



#### **8. Rehabilitation from sequelae of noma, Physionoma**

Flavie Ott, President, and Marion Catoire, Treasurer of the Physionoma association began by presenting a movie: "Rehabilitation from sequelae of noma; Keys to Smiling " produced by Lison Amiot in 2013 in Ouagadougou, Burkina Faso, with the participation of Sentinelles and their children and with financing from Winds of Hope. This film was selected for the Festival of speech therapy movies in Nancy and for a festival of African films in Besançon.

The Physionoma team had been studying the question of rehabilitation from noma sequelae since 2003. The association Physionoma is working hard to make sure that these rehabilitation techniques are passed on as efficiently as possible. For this, it offers training to carers and rehabilitators so that together they can help children with noma find the keys to smiling.

Noma develops following an oral infection in a context of malnutrition and immunosuppression. Victims are embarrassed to eat, talk and express their emotions, making social integration difficult.

A child lost part of his lip, his cheek and even his eye. He had to grow up with these sequelae and live with them. Later, he was operated on and now has a flap plugging the hole. But this does not make it any easier for him to speak, eat and smile. Even though the hole has been filled it doesn't mean that he can use his new lip and cheek. It's hard for people to understand this, and he still has trouble chewing his food. This cannot be learned alone. He needs to have rehabilitation to take advantage of the achievements of the surgery and learn how to use his new face.

During a long period of follow-up lasting several months, rehabilitation is needed to strengthen muscles, improve the mobility of the jaws, and soften tissue and scarring. This happens in a center where nurses trained by Physionoma offer rehabilitation programs that will help patients to reclaim ownership of their faces, and to eat and speak more easily. The standard procedures adopted help to maintain the mouth-opening function, increase the mobility of the face, make the flaps more supple, and take away the pain.

Rehabilitation from the sequelae of this disease cannot be improvised. Specific techniques are needed appropriate to each individual. Implementation of rehabilitation requires prior reflection, and must be founded on a rigorous approach based on carrying out tests and detailed observations. It requires close collaboration between speech therapists, physiotherapists, nursing staff and surgical teams.

Bertrand asked if this video could be posted on the WoH website. Flavie consented, but asked that this should not happen before the film festival in November.

Augustin Koara requested information on how Physionoma missions were conducted. Sylviane Columbus (Ensemble pour Eux), Caroline Benaim and Dr. Lassara Zala wondered if training could be organized respectively during surgical missions, at the Maison de Fati in Ouagadougou, and at the Persis center in Ouahigouya.

Dr. Kam Madibèlè, Hymne aux Enfants, noted that black skin has a different texture from white skin and that this has a major impact on healing.

Flavie said that Physionoma was open to collaborate with others, but stressed the importance of ensuring that the skills were transferred towards a relatively stable healthcare team.

**9. Training and awareness-raising at Tominian in Mali, Au Fil de la Vie**

Sylvie Pialoux, president of the Au Fil de la Vie association, said her organization had been in the field since 2003, exclusively in Mali, to develop training programs for health workers, and conduct prevention and community outreach. Four of the 8 regions in the country had already been covered by their campaigns - Timbuktu, Mopti, Gao and Kayes - the ultimate objective being to cover the entire country.

Sylvie presented their current 24-month program, which aimed to cover the Tominian district in Segou region and was funded jointly by Noma-Hilfe Schweiz and the Winds of Hope foundation.

The population is estimated at 2.65 million with an average annual growth rate of 3.1%. Segou region is divided into 7 districts and has 117 communes and 2,166 villages.



The Tominian district, the most westerly in the region, consists of 12 towns and 303 villages with a population of 250,000 inhabitants. It has 25 health centers, 90 health workers at various different levels, and one operational dental surgery.

Sylvie explained the reasons for choosing this district:

- Security: predominantly Catholic area, relative proximity to Bamako, and valuable contacts on site in case of difficulties.
- Malnutrition: a small district where the most recent harvest had been very bad.
- Health: centers of population close to the health center of reference
- Politics: agreement of the National Board of Health

Activities conducted are:

1. Workshop to finalize the program:
  - a. Collaboration with Ministry of Health National Health Directorate (DNS), the University Hospital Dental and Periodontal Department (CHU-OS), the National Centre for Information, Education and Communication in Health (CНИЕCS)
  - b. Pyramid training in prevention, early detection and treatment of gingivitis and noma cases at the CHU-OS, initially for the 30 Technical Directors of health centers (DTCs) and, by trickle-down, to 614 community volunteers (2 per village ) and 24 traditional healers
  - c. Community outreach screenings followed by informal discussions in the two main schools of each town as well as in public places, community health centers and any other places indicated by local authorities, to educate and inform people about oral hygiene, malnutrition and ways of preventing noma and its consequences.
  - d. Agreement with "Bhutan" radio station for regular broadcasting of messages recorded by the National Health Directorate, through the CНИЕCS
  - e. Supporting material deposited with the various agents: boxes of pictures, noma posters, prevention posters and guides, training guides, cassettes, toothpaste, toothbrushes, T-shirts, caps, notebooks and biros.

2. Reconnaissance mission to present the program to the Regional Health Directorate of Segou, the Council Chairman in Tominian, the Prefect, the Chief Medical Officer and the Directors of the "Mountain" and "Parana" radio stations.
3. Training, by Dr. Baba Diallo CHU-NOS and Nazoum Diarra DNS, of the 25 technical directors of health centers in Tominian, the Regional Director of Health for Segou, the Chief Medical Officer of the Health District, and 10 health workers from the reference health center in Tominian, with the aim of:
  - a. Strengthening the capacity of service providers in the detection, management and prevention of oral infections and noma
  - b. Giving providers the tools they need to inform, educate and communicate about noma.
4. Training of 647 points of contact and 25 traditional healers by the District Techn. Directors.
5. Community Outreach in 6 communes - Fangasso, Wan, Timissa, Lanfiala, Koula and Benena - where 2,400 people attended the screenings and discussion meetings, with gifts awarded for the best answers.
6. Awareness-raising in the 12 main schools in the communes, where 5000 students were sensitized with good answers to questions rewarded by the distribution of toothbrushes, toothpaste, hats and T-shirts, with posters and boxes of pictures being deposited with the director.
7. Donation of 25 kilos of spirulina to the DTCs in the 6 municipalities covered, to be distributed to malnourished children and anemic women.

Sylvie looked forward to the end of the period of insecurity, preparation for elections, religious celebrations, and wintering so that she could return to the field. She explained that only 3% of the population of the district had so far received training and outreach, and the program was planned to last 24 months. To Bertrand's question of how many cases of noma had been identified in the area, Sylvie answered that at this stage, there had only been one case of incipient noma and one harelip - both unfortunately now dead - and 5 cases of noma sequelae and 4 harelips that were being treated. Serious results would only appear after the training session - they took time to appear.

André Buhler of Bilifou-Bilifou said he was pleased to see that spirulina was being distributed in Mali. He explained that there are several spirulina farms in West Africa, including 5 in Burkina Faso that create some jobs and reduce the distribution of products imported by the Rehabilitation and Nutrition Education Centers (CREN). The results are very good given the very limited resources. With a price of 28 CHF per kg of dried spirulina, a treatment lasting a month costs 2.10 CHF per child.

Sylvie said that spirulina was distributed to anemic women in priority and that, for seriously malnourished children, the treatment lasts more than a month.

Rayna Robles of Antenna Technologies explained that they implement spirulina cultivation and distribution projects in association with local authorities and NGOs, but do not distribute any themselves. She indicated that spirulina can improve the quality of nutrition and was surprised that it was not better integrated into the fight against noma as a nutritional supplement. In response to an intervention from Carolina Benaim, Bertrand stated that spirulina improved the quality of nutrition, but not its quantity.

Michel Quere explained that MSF is currently supporting approximately 350,000 children in Niger who are victims of severe malnutrition (at the peak of the hunger gap) . MSF is not yet totally convinced by spirulina, especially against a massive influx of malnourished people. This requires effective and rapid response and MSF prefers to distribute Plumpy Nuts, a peanut-based food. Michel added that acute malnutrition is primarily a problem of access to healthcare, to fight against diseases (diarrhea, malaria, etc.) which are fatal in these circumstances.

**10. Surgical Missions Seen from the Nurses' Viewpoint, Ensemble pour Eux**

Sylviane Collomb, a leader in Ensemble pour Eux (EPE), said that her association, founded in 2006, carried out a dozen maxillofacial and orthopedic surgical missions per year. All those involved, committee members and operational staff alike, work entirely on a voluntary basis. Its role is to provide the medical care as well as the entertainment to accompany the surgery. All this means about sixty people per year traveling in Africa.

EPE's current partners for surgery and hospitality services are:

- Enfants du Noma, with Maison de Fati and Enfants Actions Chirurgicales,
- Dr. Philippe Bédard with Dr Zala's Persis Centre and Persis Valais of Dr. Mivelaz,
- Prof. Brigitte Pittet-Cuénod (new partnership) with Sentinelles.

The associations with which EPE works are: Enfants Actions Chirurgicales, Bilifou-Bilifou, Hymne aux Enfants and Shiphra, and the NoNoma Federation.

Financial support comes from Noma Hilfe Schweiz and Winds of Hope.

She continued by describing the different stages of organising a surgical mission.

When the mission dates are announced, nurses and community health assistants are recruited, as well as the entertainment staff, for whom no special training is required. Information meetings bring together staffs of several missions, enabling nurses and entertainment facilitators to meet, as well as refining the organization and presenting more specialised information concerning health procedures and entertainment. Clutching a mission assignment paper, each nurse and facilitator sets off with 2 x 23 kg of luggage bringing with them much of the necessary medical equipment, entertainment props, and clothing for patients and their carers.

The surgical mission can now begin! On the first day of the mission, a mass consultation is held at which all the enrolled patients are introduced to the surgeons and anesthetists. Received by a joint team of EPE and local staff, patients and their carers are categorised, weighed and measured, and their files completed. Then comes the big day, when the operations in the mission program are performed.

Patients must be informed about the decisions affecting them. All necessary laboratory and radiology examinations are then performed on the patient to be operated on, who is accompanied either by a nurse or by a facilitator. Patients who are not operated on are referred for further healthcare measures (Rehabilitation and Nutrition Education Centers, postponement to a later mission, physiotherapist, prosthetics, medical care other than surgery, etc.)

Supported by an interpreter, the nurse/facilitator explains to the patient and accompanying person about hospitalization and how the day of the operation will proceed, by talking about hygiene on the day before the operation, and postoperative problems such as pain, nausea, difficulty in urination, etc. In this way, she prepares patients whilst stressing that the team will support them and is there for them and to meet their needs. She must also explain that they will not be able to enjoy porridge the morning after...!

The nursing staff is divided into two groups:

- a. The first goes to the hospital, prepares and accompanies the patient as far as the theatre, and then takes over again in the recovery room. When the patient emerges from theatre, the nurse will therefore also assume management of the treatments that are prescribed by the surgeons and anesthetists. She will also make sure that the requirements are followed during the night when the hospital staff take charge.
- b. The second group stays at the treatment center, where 3 times a day after each meal, they distribute medicines, perform mouth care (gargles), wound care, dressings and assess progress.

It is easy to imagine that at the end of the mission, with 40 to 50 children having had operations, the nurses' pace of work is extremely intense. But to that has to be added the treatment of many conditions that must be faced: malaria, bronchitis, ear infections, etc. The doctors in charge of the reception centers, Dr.Kam or Dr.Zala are often saviors! Quite late in the evening, the surgeons and anesthesiologists come to do their rounds. Cases that pose problems or raise questions are presented to them. The nurses confirm the operating program for the following day and go and fetch the patients who are not there already to prepare them.

The nurses keep the patient's care plan up to date – it serves as a daily guide. The child's health file is also completed, and the main milestones of hospitalization recorded. The nurses have a crucial role in the consultation on the final day, and in the transmission or execution of surgeons' instructions regarding treatments, particularly as regards the future, after mission completion. They must also manage the pharmacy and all the medical equipment that has been brought along (management of expiration dates, keeping everything in order, cleaning, etc.).

The activities program, consisting of games, handicrafts, music and manual work, gives a dimension of exhilaration and distraction from the pain and anguish of the operation. This aspect of the mission was developed by adding an educational aspect, comprising both traditional schooling, aimed at maintaining academic achievement, and the teaching of best practices such as hygiene. Talks are now organized to educate patients and their carers about risk factors for noma.

There is a great deal of solidarity between the facilitators and the nurses. The healthcare treatment is complemented to a great extent by the activities program. Indeed, it frequently happens that the activity organisers observe, put their finger on a concern, a change, or a problem with the health of the child and report this to the nurses.

Ideally, and especially in connection with the disease of noma, EPE would prefer not be on the scene at all. For this to happen, awareness-raising is of paramount importance and should be a priority in all their endeavors.

Dr. Pierre Seguin and Dr. Lassara Zala thanked Sylviane for this important work that facilitates and optimizes the surgeons' mission.



#### 11. Maternity and neonatology, Persis Burkina

Dr Lassara Zala, the doctor in charge of the Persis center, first told the sad story of a boy diagnosed by a traditional healer and sent to the hospital ... during an all-out strike by medical personnel. The child's noma had fully developed by the time he was at last given some treatment. Dr Zala noted, however, the positive aspect of the training of traditional healers which was now bearing fruit.

He then explained the reasons why a new maternity unit was needed at Ouahigouya:

- Response to demand from the local population, because there is no neonatal unit between Ouagadougou and Mopti
- Prevention through monitoring and education of the mother
- Training of doctors, midwives and nurses

The Burkinabe authorities are supporting this project. Links could be developed with the newly created Subsaharan University at Ouahigouya, which includes a medical school and has just started its first year with 30 students.

#### 12. Noma Prevention and Oral Hygiene, La Voix du Paysan

Adama Sougouri, a journalist at La Voix du Paysan, presented a film on noma prevention and the promotion of oral hygiene.

« "Prevention is better than cure" it's said! Many children die in our towns and villages because they are victims of poverty, ignorance or simply the negligence of parents. Among them are those suffering from the so-called disease of shame, noma, a disease that kills silently. Children suffering from it are hidden away at the back of the huts.

A project has been implemented in schools in Burkina with the effective participation of these organisations, some of them members of the NoNoma Federation: La Voix du Paysan Radio, the Burkina Faso Persis center, Noma-Hilfe-Schweiz (NGO), the Northern Regional Directorate of National Education, and the Northern Regional Directorate of Health.

- Public radio games with the participation of children in schools
- Children's programs on mouth hygiene
- Awareness-raising theater for children in schools
- Treatment of diagnosed patients

Against a forecast of a thousand children, more than twice as many were reached: 79% of cases of advanced dental caries and gingivitis were detected. Without the Round Table of the International NoNoma Federation, this campaign might not have taken place. Thanks to Noma-Hilfe Schweiz, to the Burkina Persis Center and to other stakeholders. Unity is strength! »



**13. Noma Encounters, Phase III, La Voix du Paysan**

Dr Lassara Zala and Adama Sougouri then presented the results of the 3rd phase of the Noma Encounters begun in 2009 and financed principally by Winds of Hope.

Health is a prerequisite for survival and human development. This state can only be achieved through collective awareness. Therefore, there is a close link between the state of health of the population and its daily behavior. Access to health care for all is a major priority

The overall objective of this program is to promote the fight against noma through prevention so as to avoid the stigmatization, isolation, and exclusion of these noma-affected children in northern Burkina. The specific objectives are to:

- Inform the population widely using various means to gain a better understanding of noma
- Collaborate with all medical and social partners,
- Involve village leaders and healers,
- Educate mothers about treatment, hygiene and child nourishment,
- Contribute to referring children quickly for treatment to appropriately equipped healthcare facilities, and primarily to the Persis Pediatric Center

The strategy implemented consists of:

- Advocacy (administrative authorities and opinion leaders), 106 leaders reached,
- Mass Communication (awareness-raising in the field and by radio), 12,868 persons directly reached,
- Training (106 nurses, 68 community health assistants, 57 traditional practitioners and 22 points of contact),
- Treatment (noma and severe malnutrition).

The immediate, concrete results achieved were:

- 5 cases of acute noma recorded this year,
- 71 enfants checked to make sure they showed no signs of noma. Amongst these, 26 were suffering from necrotizing ulcerative gingivitis, which was treated at the Persis center,
- More than 60 malnourished children were taken to the Rehabilitation and Nutritional Education Center (CREN) and given restorative nutritional treatment,
- Numerous phone calls for advice and medical opinions.

The Noma Encounters program will be continued and a video produced on what has been achieved since 2009.



### **Saturday 29 September**

The Round Table re-started at 9h00.

#### **14. Noma Treatment, Mercy Ships**

Dr Peter Linz began by presenting Africa Mercy, the largest non-governmental hospital ship in the world:

- 151 meters long, 16,500 tons, formerly a Danish ferry.
- Hospital beds for 78 patients, five fully-equipped operating theatres
- Accommodation for 450 crew
- Accredited school for 55 students and children of the crew
- Scanner with 32 cross-section analyses
- Modern laboratory

He then justified the choice of a hospital-ship platform:

- Avoids competing in the long term with local health facilities - Mercy Ships only stay in a port for 10 months,
- The first facility in the world that's self-sufficient and controlled, which provides excellent surgical benefits,
- Ability to retreat quickly if necessary in cases of political instability or other danger,

- Provides the kind of facilities with which Western health professionals are used to working,
- Interactions with a country's leaders, thanks to the great impact made by the arrival of a Mercy Ship. These promote participatory development at the highest government level.

The commitment of Mercy Ships to each country takes a sequential approach which includes:

- Assessment of the country,
- Sending of prior warning about program activities,
- The deployment of the ship
- Subsequent announcement of program activities,
- Evaluation of the program

Mercy Ships has been treating patients with noma for 22 years. The organization is committed to prevention, with its child nutrition program and awareness-raising about oral hygiene. It also does reconstructive surgery and rehabilitation provided by Dr. Gary Parker, a maxillofacial and oral surgeon. The victims of Noma are found during the patient testing day, by research in the country, and by case referrals.

A total of 116 noma patients have been treated during the past five years according to the following geographical distribution:

- Guinea: 29 patients (17 adults, 12 children)
- Togo: 15 patients (11 adults, 4 children)
- Sierra Leone: 32 patients (21 adults, 11 children)
- Benin: 9 patients
- Liberia: 31 Patients

Since 1990, Mercy Ships has performed 1'655 reconstructive operations on 498 noma patients in West Africa.

Mercy Ships was looking for partnerships with other organizations in the Federation to treat noma patients. Philippe encouraged members to respond to this offer.

To a question from Flavie, Peter replied that patients are hospitalized on the boat for the time deemed necessary, from a few days to a few weeks, and then transferred to health facilities in the country. Follow-up operations can be performed during the same mission, or during the next mission in the neighboring country.

#### **15. Surgical treatment of noma, AEMV**

Prof. Brigitte Pittet-Cuénod, a surgeon in the Department of Plastic, Reconstructive and Aesthetic Surgery at the University Hospitals of Geneva, and a member of the Association for Facially Mutilated Children (AEMV), explained the importance of collaboration between hospitals, the AEMV and the NGOs – the Sentinelles and Hirtzel Foundations, Terre des Hommes and Hymne aux Enfants. AEMV's humanitarian activities are divided between research programs on noma, humanitarian missions and transfers (*to better equipped hospitals*).

The first mission to Niger to monitor patients who had had surgery took place in 1994. During surgical missions to Zinder in 1996, 1999, 2003, 2005, 2009 and 2011 and to Niamey in 2012, 116 children with sequelae of noma and 72 patients with cleft lips or cleft palates were operated on. Because of the security problems in Niger, the next mission would be to Burkina Faso in November 2013.

These missions are characterized by very rudimentary local conditions. They are organized for cases with limited tissue loss who have been treated with locally applied flaps. Brigitte then described in a highly educational manner the surgical techniques used in ten cases and the way in which mouth-opening had progressed over ten years.

The transfer elsewhere of complex cases is justified when microsurgery, an intensive care unit, or reconstruction in several stages is required. Conditions for this are reduced costs, short hospital stays and a reception center for post-operative care. From 1984 to 2013, 206 children with noma sequelae and 42 children with craniofacial malformations, congenital or acquired, were transferred and treated at the University Hospital in Geneva.

In conclusion Brigitte identified three positive points:

- Teaching and knowledge transfer
- Collaboration
- Between hospitals and NGOs
- Amongst NGOs - Sentinelles, AEMV and Terre des Hommes
- Between surgeons, anesthetists and nurses
- Ethics, spirit of cooperation and professionalism

And some great news! Free hospital care has been obtained from the University Hospital in Geneva for 15 patients per year from three NGOs: Sentinelles, Terre des Hommes and Hymne aux Enfants.

Philippe admired the reparatory work done by the AEMV team. This also reinforced for him the prevention mission assumed by WoH. Brigitte thanked him but stated that as long as the standard of living remained so low, the two aspects, prevention and surgery, would remain necessary. She added that she had been disappointed in the past by the conflicts between NGOs, but was now happy to see that there was real collaboration within the Federation.

Dr Pierre Seguin of Enfants du Noma congratulated his colleague Brigitte and confirmed that the noma cases presented did indeed require a transfer.

To a question from Andre Buhler, Brigitte replied that donor transplants were as yet not possible, mainly because of the risk of graft rejection and the difficulty of providing medical care in the patient's country. External bone prostheses are also still excluded in cases of reconstruction of noma sequelae because they do not yet seem to be reliable enough.



**16. Monitoring record card for surgical missions, Gesnoma**

The record card for tracking patients operated on for noma was developed and finalized during the 2011 Round Table. Last year, Dr. Denise Baratti-Mayer had expressed regret that NGOs, except for Sentinelles, did not use this tool, since this correspondingly reduced all the lessons that could be learnt from such a database. To demonstrate the effectiveness of this approach, Denise explained the record cards for the surgical missions conducted in collaboration between Sentinelles, Operation Smile and the HUG surgical team, with returns at six months and two years.

The surgical missions in December 2010 to Niamey with Dr. Servant and his team from Operation Smile and to Zinder with Prof Pittet-Cuénod, Dr. Martin, Dr. Schmidt and the HUG team enable a few cases to have been followed up for 2 years:

- OB , born in 2002, acute-stage noma diagnosed in 2004 by Sentinelles, partial loss of nose, cheek and jaw bones ; operated on by the HUG Team, outcome at 6 months 5/5 - small repairs ; follow-up after 2 years 5/5 - case completed.
- MM, born in 2001, acute-stage noma diagnosed in 2005 by Sentinelles, partial loss of lips, cheek and jaw ; operated on by the HUG Team outcome at 6 months : not measurable – alterations made; follow-up after 2 years: aesthetic 4/5 - functional 5/5 - massages to continue
- TH , born in 1976 , noma in 1978, identified by Sentinelles in 2008; partial loss of lip, cheek, nose and jaw ; operated on by the HUG Team; outcome at 6 months 5/5 ; follow-up after 2 years 5/5 - case completed
- MI , born in 1994, noma in 1998, identified by Sentinelles in 2008; partial loss of lips and cheek; operated on by the Operation Smile team; outcome at 6 months 5/5 ; follow-up after 2 years 5/5 - case completed
- TR, born in 2000 , noma in 2002, identified by Sentinelles in 2008; complete loss of lips and chin, and part of lower jaw; operated on for the 3rd time by the Operation Smile team; outcome at 6 months 5/5 ( drooling and aesthetics) - 4/5 (eating, drinking, talking ) follow-up after 2 years 3/5 (aesthetics) - functional outcome not assessed, alterations to be done

The surgical missions of January 2012 to Niamey with Prof Pittet-Cuénod and the HUG team enable other cases to have been followed up for 6 months:

- H.R., born in 2004, identified by Sentinelles with acute noma in 2005, partial loss of corners of mouth and a small part of the cheek; aesthetic outcome at 6 months 4/5 - functional 5/5 – probable need for small alterations
- N.H., born in 2003, identified by Sentinelles with acute noma in 2006; partial loss of lip and cheek; outcome at 6 months 5/5 - case probably finished
- M.B., born in 1982, noma in ?, identified by Sentinelles in 2010; partial loss of upper lip; aesthetic outcome at 6 months 4/5 - functional 5/5 - probable need for alterations
- H.S., born in 2007, identified by Sentinelles with acute noma in 2011; loss of lip, part of the nose and slight constriction; aesthetic outcome at 6 months 4/5 - functional 5/5 - alterations to be planned
- S.S., born in 1993, noma in 2000, identified by Sentinelles in 2011; loss of lips, cheek, part of chin, and constriction; outcome at 6 months 5/5 – mouth-opening progressing, from 40 to 52 mm

Denise took stock of the record card:

- It's a good working tool and it's in use
- Take care when taking photos, backgrounds and dates of photos - this is a big job for Sentinelles and Gesnoma
- At the moment it's used only by Sentinelles in collaboration with the teams of Dr. Servant and Prof. Dr. Pittet-Cuenod

Marie confirmed that the workload for Sentinelles was not too heavy, because regular checks were made, and it was just a question of copying out the data on the cards.

An appeal was made to Enfants du Noma to also fill in these cards and so also supply details to this valuable source of information. It was stressed that this work did not have to be done retrospectively. It was just a question of introducing the record card for future missions. Dr. Pierre Séguin undertook that Enfants du Noma would get organized to fill in these cards on future missions, and in particular the one that would take place in Ouagadougou in November 2013.

WoH would send the most recent version of the record card by email to all Federation members.

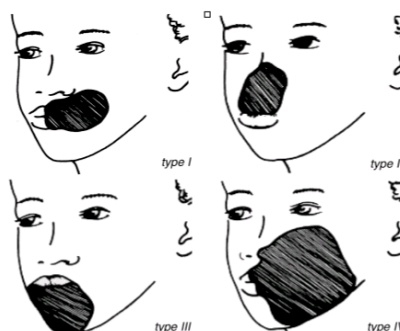
### 17. Classification of the stages of noma, Winds of Hope

In the previous workshop, Philippe had asked that consideration be given to a classification of the different stages of noma that would allow us at least to distinguish between the gingival stage, incipient noma and the sequelae, and to present it in different ways, as a function of the audience being addressed: the community, operational personnel and scientific staff.

Gesnoma, WHO and the FDI had then volunteered to draft a proposal. Since the WHO was absent, Philippe asked Denise Baratti-Mayer and Virginie Horn to give a situation report on their deliberations.

Virginie Horn, head of training at the International Dental Federation proposed building on the methodology that the IDF used for the classification of caries. She indicated that there was indeed a third axis to the classification, lesion type, which had already been well defined by Prof. Montandon in 1991.

Figure 1 : Classification des séquelles de noma.  
Selon Montandon, 1991.



Lésion de type I : défaut jugal localisé  
Lésion de type II : amputation du nez et de la lèvre supérieure  
Lésion de type III : amputation de la mandibule et de la lèvre inférieure  
Lésion de type IV : défaut massif de la joue, du nez, des lèvres et de la structure osseuse



The FDI proposal would be to draft a document describing differentially the stages and types of lesions, in language suitable for the audience using it - community, operational personnel or scientific staff.

<b>Community Level</b>	To help and support parents and relatives, community health workers, etc. to detect cases of noma, to assess the severity of the cases and refer children to care for proper care.
<b>Operational Level</b>	Clinical diagnosis and treatment by healthcare professionals
<b>Scientific Level</b>	Description and criteria for the different stages of noma

In turn, Denise began by making an educational presentation on the way a gum progresses from a healthy state to acute necrotizing gingivitis (ANG) and then to incipient noma, necrosis, scarring and finally the aftermath. She concluded with the following proposal for classification:

	Signes	Durée	Traitement	Réversibilité
Gingivite simple	Gencive rouge, enflée	Indéterminée, longue	Soins locaux	OUI facile
GNA	Disparition papilles Ulcère et nécrose Saignement sp.	Indéterminée	Soins locaux Antibiotiques Renutrition	OUI plus difficile
Stade 1	Exposition os en bouche Oedème facial	Quelques jours	Soins locaux Antibiotiques Renutrition	OUI si ttt rapide et correct
Stade 2	Nécrose	Quelques jours à quelques semaines	Soins locaux Antibiotiques Renutrition	NON
Stade 3	Chute nécrose Début cicatrisation	Quelques semaines, mois	Soins locaux Physio.	NON
Stade séquellaire	Plaie cicatrisée		Physio.	NON

	Symptoms	Duration	Treatment	Reversibility
<b>Simple gingivitis</b>	Red, swollen gums ;	Indeterminate, long ;	Topical treatments ;	YES, easily
<b>ANG</b>	Disappearance of papillae, ulceration & necrosis; bleeding	Indeterminate;	Topical treatments Antibiotics, Renutrition	YES, more difficult
<b>Stage 1</b>	Exposure of bone in mouth Facial edema	A few days	(idem)	YES, if correct treatments given quickly
<b>Stage 2</b>	Necrosis	A few days/weeks	(idem)	NO
<b>Stage 3</b>	Necrosis drops off Formation of scar tissue	A few weeks/months	Topical treatments Physiotherapy	NO
<b>Sequelae stage</b>	Healed wounds		Physiotherapy	NO

In answer to a question from Richard Colomb, Ensemble pour Eux, Denise said that halitosis already appeared at the ANG stage, as well as hyper-salivation. Both were symptoms to be reported.

Sady Kipasa from Non au noma en RDC confirmed that if ANG with halitosis was detected an immediate response was necessary, because it is a characteristic of noma.

Philippe reminded everyone that the aim of this approach was to enable professionals to identify, quickly and remotely, the stage of the disease on the basis of simple but objective observations made on site, so as to guide the patient towards the appropriate healthcare facilities.

Dr. Pierre Séguin stressed that the attack on bone structure at Stage 1 is only a matter of one to three days, and you have to be there just at the right time to detect it. Marie said that Sentinelles quite often detects cases in Stage 1 at the time of onset of bone necrosis, just before skin necrosis. Denise confirmed that skin lesions characterize Stage 2.

Priscilla Benner of Mama Project noted that in the current WHO classification ANG is presented as being in Stage 1. Denise supported this approach, which could have the advantage of not changing the work already done too much and upsetting working practices in the field.

Dr Bernard Mivelaz of Persis Valais proposed that we add an additional column providing for further investigations such as anemia, HIV, tuberculosis, etc. based on the idea that ancillary pathologies can accelerate the onset of noma. Denise thought that too complicated and aimed at another objective, parasite research.

Philippe summarized for the Gesnoma-FDI working group three matrix axes for what Winds of Hope wished should quickly become a reference tool in the definition and description of noma:

The 3 target populations are :

- Communities : Community Health Workers, Families, Villages (NGO responsibility)
- Operational : Nurses, Health Centers (CSPs), hospitals (WHO responsibility)
- Scientific : studies, research (Responsibility of experts)

The stages of development could be the following :

- Stage 0 : simple gingivitis = dental – reversible
- Stage 1 : ANG = first signs of noma – reversible
- Stage 2 : Edema and exposure of bone in mouth = noma – reversible
- Stage 3 : Necrosis of tissue = noma – irreversible
- Stage 4 : Necrosis drops off, scar tissue begins to form = noma – irreversible
- Stage 5 : Scarring = sequelae of noma – surgery

Finally, the description of the types of lesion could be based on that done by Prof Montandon in 1991.

Once this classification was complete, and based on the excellent work of MSF and Sentinelles, similar work could be undertaken on the various treatment protocols, for each of the stages encountered, and tailored to the requirements of the different levels of people involved.

#### **18. Aviation Sans Frontières**

The work done for the members of the NoNoma Federation by the medical supply teams of Aviation Sans Frontières (ASF) had not been much mentioned by speakers. Yet their sensitive handling of children who are often afraid during transfers by plane, as well as their transportation of medical supplies, drugs and milk powder is tremendously valuable.

Michel Poitevin gave a few examples of ASF's work:

- Transfers of children to be operated on by AEMV at the HUG (Geneva Hospital)
- Delivery of 455 parcels containing 2'716 kg of milk powder for Hymne aux Enfants in Burkina Faso in 2011
- Delivery of a radio block for Dr Zala of Persis in Burkina Faso
- Repatriation to Paris of nearly 5,000 noma posters, packaged in 248 rolls of 20 posters, and delivery to 5 African destinations in 2011

Sylvie recalled that she got to know about noma when working as an ASF loadmaster.

The Assembly expressed its warmest thanks to ASF for their valuable collaboration.

#### **19. Human Rights – Winds of Hope**

The Annex to the resolution passed in 2012 listed the obligations of States in the fight against noma. The resolution and its annex are available on the WHO website. Philippe stressed that NGOs in the Federation should not forget when speaking with various government authorities to remind them of their obligations.

Every 3 years, countries have to present a report on their human rights situation and progress made. Since the adoption of this resolution, countries have to report on measures taken to prevent noma. WoH will work with the commission charged with evaluating the reports on situations and progress made in the fight against noma.

The foundation will inquire about the dates on which the countries affected by noma have to submit their reports, and will offer Ministries of Health help in preparing them.

#### **20. Internet Site – Winds of Hope**

Philippe indicated that the French version of the new WoH website was released in February 2013 and the English version in April 2013. The German version is being translated. All minutes of general meetings and round tables since 2009 are available on the WoH site under "Act and join forces" and then click on "International NoNoma Federation".

The time had therefore finally arrived for WoH to address updating the nonoma.org website. This renovation should be faster, because the technology work done for the WoH website can be directly reused for the Federation. The technical partner had been appointed as well as the designer, who will retain the same color basis as for the current site.

Members will be invited to make contributions to enrich the site. A link to their own website, or a dedicated web page for those who do not have one, will be available when you click on their name or logo. This will give associations who have an Internet site greater visibility, and an Internet presence to those who do not. The content of these pages will be the responsibility of members. Everyone will therefore be able to upload their newsletters and activity reports, or create a link to them, in accordance with the requirements of the Federation's Constitution.

In order to strengthen the ties between the members of the Federation, Ariane Vuagniaux proposed that WoH take responsibility for issuing a newspaper or newsletter, in line with what had been the WHO's "Noma Contact" which had ceased to appear in 2008. This communication tool would have a dual purpose: to enable stakeholders in the fight against noma to enhance their synergy and collaboration by being better informed and to raise awareness of the disease and of the fight against noma beyond the small circle of those involved.

Philippe thought that this project should be coordinated with the content of the new and future "news" page on the NoNoma website, which will include key events, news, calendar, etc., as well as links to social networks. In agreement with WoH, Ariane would draw up a proposal to determine scope and funding.

## **21. Members' Open Forum**

Dr. Sady Kipasa of Non au noma en RDC, presented the fight against noma in Congo – Kinshasa, which had made a formal request to receive a WHO national noma program funded by WoH. Sady needed official support and financial assistance to continue his activities in the fight against noma. He had just made a plea for this fight:

[https://docs.google.com/file/d/0B4aPEh3E-BNFV2hpQWFDaG1wNW8/edit?usp=drive\\_web&pli=1](https://docs.google.com/file/d/0B4aPEh3E-BNFV2hpQWFDaG1wNW8/edit?usp=drive_web&pli=1)

Sady planned to visit the area at war, and in which many cases of noma are reported, to conduct a more specific investigation. Poverty is extreme in those areas where conflicts persist and people are constantly displaced. These data are important to justify the deployment of surgical missions. Sady recently treated 3 cases of fresh noma in Kinshasa. He thanked WoH for financing a vehicle last year to facilitate his movements.

Dr. Brigitte Pittet-Cuénod of AEMV, said that the 2014 Dental Surgery Congress would take place in Geneva. As President, she was responsible for organizing this event. She wanted to promote the theme of humanitarian aid, and offer NGOs the opportunity to take a stand in the exhibition hall.

Before closing the discussion, Philippe stated that henceforward this event would take place annually on the last weekend of September, subject to unforeseen circumstances or clashes with other events. He then paid tribute to all the participants for the quality and richness of the debates that had marked the two days. He also expressed his gratitude to our loyal and valuable volunteer interpreter, Marianne Wanstall, to our minutes secretary, Ariane Vuagniaux, and to the organizer of the Round Table, Carole Ballanfat.

Finally, Philippe gave the floor to Augustin Koara, a nurse at the Maison de Fati, to share his experience as a sick child, his treatment, his recovery and his current work. This story was heard with much emotion by the assembly. Augustin then told a little tale to encourage collaboration between NGOs, such as the one he had benefitted from in his life-story:  
« One day a fire broke out in a forest and all the animals panicked and ran around all over the place. Only a hummingbird flew to the stream to fetch a drop of water, which he carried in his beak and threw on the fire. The armadillo said he was crazy because he could not do anything with a drop of water ... but the hummingbird replied that if each of the animals brought along a drop of water the fire would be extinguished. ».

Augustin concluded by singing his message of prevention:

« On behalf of Winds Of Hope and the NoNoma Federation, together we stand up to fight noma, which continues to wreak havoc on children already humiliated by extreme poverty. We, African Boys, lend our voice to eradicate this terrible disease! »  
« Dear friends and relatives, lend us your ears.  
This disease noma kills many of tender years.  
If your child has mouth pain, if his mouth swells,  
If he has mouth sores, with bad smells,  
Don't hesitate, don't wait. See your practitioner! »

Noma is a dangerous disease, noma is a dangerous disease.  
Noma is a terrible disease, noma is a terrible disease (refrain).

Noma is a gangrenous stomatitis of the face,  
Starting from the gums, it gnaws the nose, and then the lips,  
Destroys the teeth, the cheeks and even the eyes.  
Oris cancrum noma, which comes from the Greek term nomein meaning "devour".  
In Burkina Faso, noma is called in the national languages:  
Roulogou, yimbse, dioula kolon, in foulfoude baswii, to koulpelogo boofr or dindine.  
By some Nigerian ethnicities tzizal which means "one who smells bad"  
When the mouth of a child with noma exudes fetid and foul breath  
He needs to be treated!

Refrain and other verses are at : <http://www.youtube.com/watch?v=D18zyta6bgU> »

Philippe wished everyone a safe journey home and looked forward to seeing everyone next year.

The Round Table was adjourned at 13:30.



The Presidency :  
Winds of Hope

Lausanne, October the 16<sup>th</sup>, 2013