

**Present:** A Better life Foundation, Au fil de la vie, Aviation sans frontières,  
Enfants du Noma, Ensemble pour eux, GESNOMA,  
Hilfsaktion Noma, Hymne aux Enfants, Idées'Elles,  
La Voix du Paysan, MAMA Project, Noma Hilfe Schweiz,  
Persis Burkina, PhysioNoma, Sentinelles  
Winds of Hope.

**Invited :** OMS-Afro (partially present)

**Excused :** Brian Jones, Antenna Technology, AWD stiftung,  
Dutch Noma Foundation, Enfants du monde Côte d'Azur,  
Facing Africa, Fondation Hirzel.

**Represented :** Association d'Entraide des Mutilés du Visage by GESNOMA,  
Association Hymne aux Enfants Belgique by the Foundation Hymne aux  
Enfants.

The 8<sup>th</sup> Round Table (below RT) is opened at 9.15 am.

1) Adoption of the minutes of the 7<sup>th</sup> RT 2008

The RT unanimously adopts the minutes of the session of September 6th, 2008.  
Ariane Vuagniaux and Renata Ecuillon are thanked for its writing.

2) Results of GESNOMA's study

Presented by Dr Denise Baratti-Mayer, GUH plastic and reconstructive surgery department, this study, led by a multidisciplinary team of the Geneva Study Group on Noma, was conducted on 55 children in Niger from 2001 to 2006 in collaboration with Sentinelles and the financing of the Hirzel Foundation.

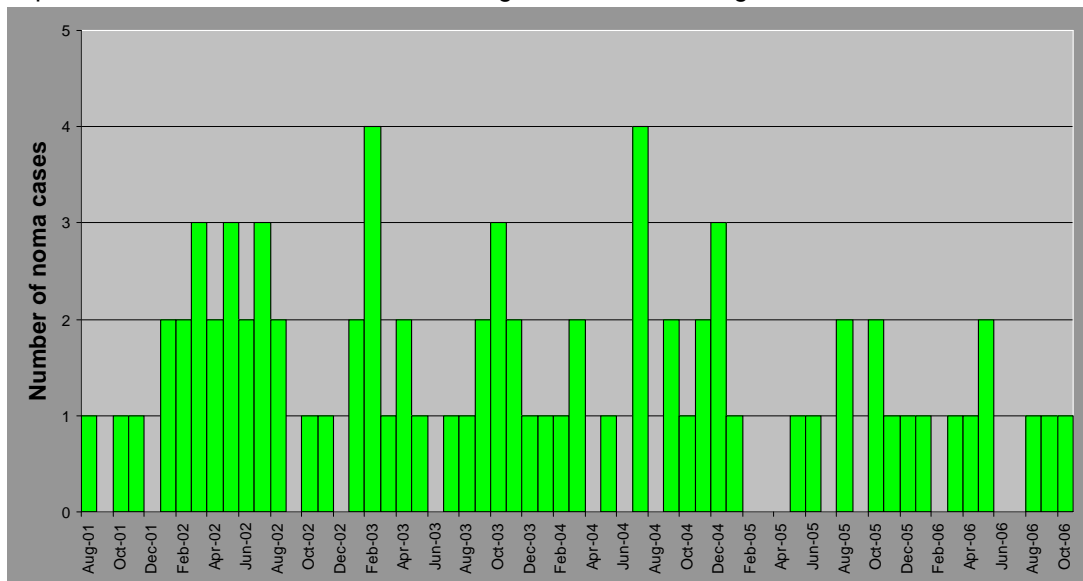
The combination of poverty, malnutrition, diseases and lack of oral hygiene causes acute necrotizing gingivitis (ANG). The study shows significant differences between oral bacteria in healthy sites and those of diseased sites, but not between healthy and sick children. However, it failed to identify a bacterium associated only with noma but it supports the hypothesis that noma develops on a previous ANG.

Noma has characteristics of an opportunistic infection involving quantitative rather than qualitative changes in the bacterial balance.

This study shows that noma is associated with a chronic malnutrition, a recent infectious pathology (malaria) and a precarious environment (overcrowding, large families). It is particularly shown that the risk of noma increases significantly from the 4th child. In the presence of large families, prevention at the level of pregnant mothers health appears as an extremely important priority.



Epidemic curve of the cases of noma diagnosed between August, 2001 and October, 2006



Charlotte Faty Ndiaye would like a similar study could be conducted in southern Africa where noma is closely linked to AIDS. The fact is that the AIDS test was not retained for ethical reasons in the study of Gesnoma and that Winds of Hope does not want to intervene in countries where the political situation is worrying.

In the discussion that follows, Bertrand Piccard requests to schedule at the next Round Table a discussion on ethics to be observed towards HIV-positive children suffering from noma.

In Burkina Faso, Sentinelles is confronted with an increase of new cases of noma among HIV-positive children.

### 3) Presentation of PhysioNoma: missions and rehabilitation

Presented by Marie Pocachard and Emilie Tissot, the creation of PhysioNoma in 2003 arose from the need for speech therapy care of patients operated of noma.

Their actions are aimed at informing healthcare professionals about noma, to rehabilitate patients suffering from noma in pre-and postoperatively and to train local health care teams in this specific rehabilitation.

The volunteer speech therapists and physiotherapists treat the disorders of articulation, phonation, labial continence and mandibular mobility by a passive and active rehabilitation for a pain reduction and a functional improvement.

A successful care is inseparable of a long and regular follow-up with stable and trained local medical teams.



Their missions began at first in Niger then in Burkina Faso in association with Sentinelles and Hymne aux Enfants. Physionoma is opened to other collaborations.

All relevant documents are on [www.physionoma.fr](http://www.physionoma.fr)

3) Presentation of the Foundation Bernard Costin and the Association Remy Conte nous pourquoi

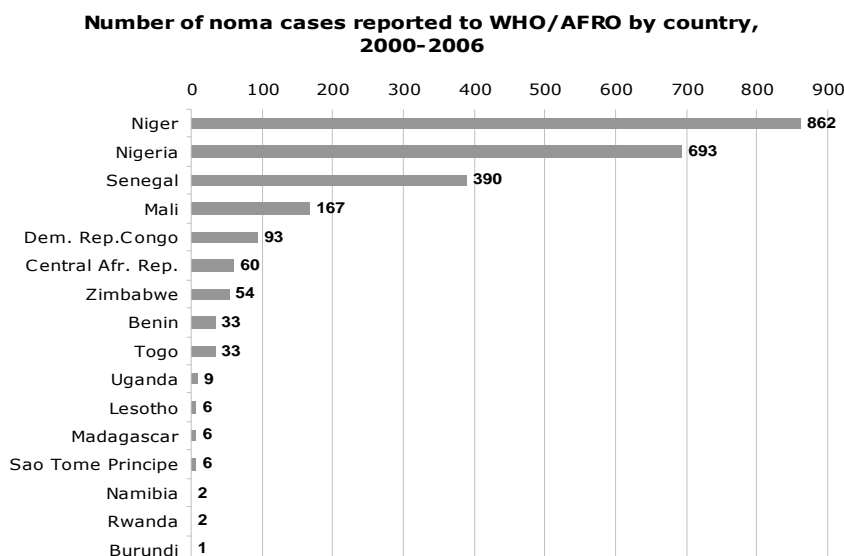
Presented by Dr. Bernard Costin, Enfants du Noma, and by Framboise Conte, the Foundation and the Association, that have just been founded, follow the same goal : to improve the life quality of the most miserable populations around the world, and especially the victims of Noma, and to fight against other plagues of malnutrition or deep poverty. The activity of the Foundation is to make the link in a non profit-making way between donators and associations fighting against the same plagues.

4) Prevention and monitoring of the Noma in Nigeria by MAMA Project

Presented by Dr. Priscilla Benner, this training program of health agents aims at promoting the distribution of essential micronutriments to fight against the malnutrition of children and mothers. This action takes place in close cooperation and coordination with the Ministry of Health, the NGOs and other aid associations and volunteers.

5) Noma in the African region by the WHO and the GUH

Presented by Charlotte Faty Ndiaye and Dr Denise Baratti-Mayer, this study launched in 2007 by AFRO WHO aims at obtaining an African map of the noma.



1998 epidemiological study concluded in the development of 140'000 new cases a year, in 20 children affected out of 100'000, in 770'000 survivors and in a mortality rate of 70 to 80 %.

2007 study, based on cases of noma listed between 2000 and 2006, shows that 39 out of 46 states are affected by the noma with a total of 2'620 cases and 82 deaths reported. Five countries reported more than 100 cases: Niger 862 cases, Nigeria 693 cases, Senegal 390 cases, Burkina Faso 174 cases and Mali 167 cases. Niger and Nigeria account for 59 % of cases.

6) Noma documentary in Niger of the Irish TV in the serie "what's the world "

Presented by Patrick Joly, Sentinelles, this beautiful documentary reports with great sensitivity of the reality of Noma as lived and told by the Africans themselves.

The 8th TR is stopped at 12.30 pm for lunch in common and starts again at 1.45 pm.

7) The Word to the members

The first points are taken back from discussions opened at the previous RT. The absence in the afternoon of Charlotte Faty Ndiaye, AFRO WHO, is unanimously considered regrettable by the assembly, considering the points to be discussed.

a) Development by the Federation of a common material for prevention and early detection.

The WHO has difficulty in finalizing and supplying a common material of prevention and early detection. This problem is recurrent and distresses several members but should not be a sticking point for the Federation. On the opposite, the Federation needs common projects which structure it, and the elaboration of this material may be one.

The discussion is followed by a proposal for action in three stages that Winds of Hope will coordinate:

1. Sending an inventory sheet to be completed by each member to identify their educational materials and specifying conditions of use (subject, medium, target country, target, context, language, possible corrections, origin, name of association, etc.). The WHO existing equipment will be included in this census.
2. Elaboration of a library project which will be submitted to each member for any corrections, remarks, comments. Each member will then give the conditions for free use of his material.
3. Valuation of this material by a centralized production while allowing each member the possibility of reproducing by adapting the material of interest according to their local needs.

This proposal is unanimously accepted.

Further to Patrick Joly's question, Sentinelles, Winds of Hope will ask the WHO where are the posters of prevention of Noma which the members ordered following the 2008 General Assembly.

b) Training on Noma in the national schools of health and professors' schools

The role of the WHO is essential to make recognize these trainings on the noma by the official national authorities of every country and obtain the support of the national coordinators in this process.

The WHO had announced the elaboration of a training manual for the health agents.

This document has not been existing yet.

Winds of Hope will intervene with the WHO for an update on this subject and to set a timetable.

Marie Pocachard informs that PhysioNoma was approached by the Ministry of Health of the Burkina Faso to provide the male nurses a module of training in rehabilitation. But this only makes sense if there are then positions allocated to this rehabilitation, so that it effectively takes place. The contacts have remained there for the moment.

Ute Winkler-Stumpf forwards to Philippe Rathle a copy of the training manual in 3 modules used by Hilfsaktion Noma and validated by the official authorities of Niger and Guinea Bissau.

Dr. Bernard Mivelaz and Jean-Pierre Philippe Leupin give Philippe Rathle under electronic form three manuals (of the trainer, of training course, of reference). Philippe Rathle thank them and assure them that these manuals will serve him well in his discussions with WHO and will be well placed in the library discussed above.

c) Creation by the Federation of a unique questionnaire of follow-up and evaluation of operated children, in the idea to create a database

Dr. Denys Montandon asked Dr Denise Baratti-Mayer to present us a first project of questionnaire noma which he elaborated. This one having had to leave in the afternoon, Ariane Vuagniaux is in charge of making the presentation:

**Projet de fiche patient noma**

1. Numéro de dossier
2. Non, prénom, date de naissance
3. Diagnostic (type de lésion selon classif. DM)
4. Mesure de l'OB préopératoire
5. Photos préopératoires
6. Rubrique opération 1
  - lieu et date
  - nom du / des chirurgiens
  - type d'anesthésie
  - gestes effectués
7. Rubriques interventions successives
8. Complications
9. Physiothérapie
10. Résultats à court terme avec photos
11. Evaluation de l'amélioration esthétique et fonctionnelle
12. Résultats à long terme avec photos

À remplir  
uniquement par  
le chirurgien

The oral opening must be measured of osseous edge to osseous edge on the median line (of the middle of the mouth). If the bone is not visible, we go of gingival edge to gingival edge by pressing slightly on the gum.

We never measure the oral opening by taking teeth as a mark !

Dr Denise Baratti-Mayer specifies that the purpose of this questionnaire is purely statistical and not medical.

**Comments approved by the assembly were the following ones:**

- a) Add the establishment date of the form
- b) Add the name of the NGO and/or the reception center of the child
- c) Add the nationality and the ethnic group of the child.
- d) Add a brief medical history of the disease and the previous pathologies
- e) Concerning the measure of the oral opening, how to make when there are not bones anymore. It would be necessary to make plans.
- f) Replace the term "physiotherapy" by "rehabilitation"
- g) How to estimate the aesthetic and functional improvement without being subjective? It would be necessary to find some simple questions to ask to the patient himself : how does he judge, on a scale from 1 to 5, his capacity to eat, drink, speak normally or his family, social and professional reintegration.

Ariane Vuagniaux will forward these comments to Dr Denys Montandon through Dr Denise Baratti-Mayer.

d) Intranet of the Federation

The intranet such as it was implemented aimed at being a privileged forum between the members. We have to admit today that it is used only by very few members and very rarely.

Philippe Rathle suggests adapting it in an information platform for the members, allowing everyone to file their documents (statutes, reports, minutes, presentations, etc.) in a personal directory which would be accessible to the others. A Federation directory would include not only its own documents but also all the collaborations and the common actions.

Every member would specify if he allows only the reading or the copy of his documents. An e-mail would warn automatically the other members of the filing of a document in a directory and would provide the link.

**The assembly approves unanimously this proposal.**

e) Miscellaneous

Further to the discussions of the day before at the General Assembly, Ute Winkler-Stumpf will be responsible to contact the Campaner foundation as well as the G.I.G.I.P. of Dr Vincenz, both absent for more than two years, to ask them about their future in the Federation.

A contact will also have to be established with the NGO Non au Noma en RDC.

In conclusion of this busy day, Philippe Rathle thanks warmly all the members for the quality of the presentations and the exchanges which took place, as well as for the excellent state of mind which prevailed during these two days. He assures that the Federation can count on the new team in place at Winds of Hope.

Flowers are given to Marianne Wanstall for her participation as voluntary interpreter and a knife Victorinox Winds of Hope signed by Bertrand and Brian for Ariane Vuagniaux for taking notes to prepare these minutes.

**Minutes of the  
8<sup>th</sup> Round Table of  
October 30<sup>th</sup>, 2009  
in Ferney-Voltaire**

Bernard Mivelaz thanks in his turn Philippe Rathle for the quality of his leadership in the debates.

The Round Table is closed at 3:45 pm

The President:

Bertrand Piccard

The Director:

Philippe Rathle

Lausanne, January 18, 2010