

## **Present**

- Presidency: Winds of Hope (WoH).
- Active Members: A Better Life Foundation, Au fil de la vie, Aviation sans frontières, AWD Stiftung Kinderhilfe, Dutch Noma Foundation, Enfants du Noma, Ensemble pour Eux, Gesnoma, Hilfsaktion Noma, Hymne aux Enfants, Idées'Elles, Label Vert, La Voix du Paysan, MAMA Project, Noma-Hilfe-Schweiz, Non au Noma en RDC, Persis Burkina, Persis Valais, Peter Ustinov Stiftung, PhysioNoma, Project Harar, Sentinelles.
- Partner Members: WHO Afro, FDI.
- Associate Members: Centre Nopoko, Prométhée.

## **Guests**

Bilifou-Bilifou, La Maison de Fati, Médecins Sans Frontières (MSF), Jean Ziegler (Human Rights), H.E. Prosper Vokouma (Ambassador of Burkina Faso to Switzerland and the United Nations in Geneva), Tamara Pelège (interpreter).

## **Apologies**

Antenna Technology (represented by Winds of Hope), AEMV (represented by Gesnoma), Enfants du Monde, Facing Africa (represented by AWD Stiftung Kinderhilfe), GIGIP (represented by Gesnoma), Marianne Wanstall (interpreter)

## **Friday 28 September**

The Round Table (henceforth RT) was declared open at 15h00 by the presidency, Winds of Hope (henceforth WoH).

### **1. Adoption of the Minutes of the 10th Round Table 2011**

Following what had been a very busy year for him, Philippe Rathle presented his apologies to the Assembly for the very late distribution of the French version of the Minutes of the 2011 RT. In addition, the translation of these minutes into English had not yet been finalised. Their formal adoption would therefore be postponed until the 2013 RT, so as to allow members to make observations and comments.

### **2. Persis Burkina et Valais – Maxillofacial surgical campaign to Ouahigouya in Jan 2012 at the Paediatric Medical & Surgical Centre of Persis (CMCPP) Exemplary coordination and synergy within the Federation**

Dr Lassara Zala, director of the CMCPP, introduced the other campaign organizers :

- Aïssata Zala, executive secretary of both the CMCPP and the campaign ;
- Dr Bernard Mivelaz, coordinator ;
- Christine Allary, representing Enfants du Noma (surgical team) ;
- Sylviane Colomb, representing Ensemble pour Eux (pre- and post-operative care) ;
- Karim Zongo, responsible for the CMCPP operating theatre.

Then, he introduced the other members of the Federation involved in this campaign :

- A dozen children and their carers were transferred from Mali to Ouahigouya and then repatriated by Alkalifa Toure and his association Alnovie, under the responsibility and coordination of Ensemble pour Eux, and thanks to funding from Winds of Hope;
- Winds of Hope provided financial assistance to Ensemble pour Eux for their prevention and care of noma during this campaign;
- La Voix du Paysan, Sentinelles, A Better Life, Hymne aux Enfants and Nopoko Centre participated in the identification of children requiring surgery;
- Noma Hilfe Schweiz helped to finance Persis;
- Aviation Sans Frontières facilitated the delivery of materials.

Dr. Zala then explained the sequence of operations during the campaign:

- Identification of patients
- Project planning with stakeholders
- Preparation of the operating theatre
- Pre-admission care
- Examination on admission
- Surgical operations
- Post-operative care
- Return home
- Long-term monitoring

Finally, he described all the resources available to CMCPP for a surgical campaign:

- Operating theatre: two operating rooms, one sterilization room, one recovery room, 3 offices for consultations (surgeons and anesthesiologists), one room for plaster-casts and other treatments, two changing rooms, one meeting/dining room, 8 in-patient beds and one store-room;
- Laboratory, Medical Imaging, Dental Surgery, Accommodation for missionaries, Dormitories, Administration, Transportation and Waste disposal.

Thanks to this cooperation amongst several associations, 52 children were operated on during this surgical campaign in January 2012, including 19 for noma sequelae.

Christine Allary of Enfants du Noma and Valérie Maeder of Ensemble pour Eux intervened to acknowledge the excellent spirit of cooperation that had prevailed during this campaign.

### **3. Sentinelles – Help for children with noma Zeinabou - 10 years of support**

Manon Chatelain, in charge of Niger, first presented a review of Sentinelles' work combating noma :

- in Niger between 1992 and August 2012: 903 children
- In Burkina Faso between 1991 and August 2012: 312 children

She then expanded on the principles and philosophy of Sentinelles' activities, illustrating these with the monitoring and support of a little girl named Zeinabou:

- In September 2002 at Zinder, Zeinabou, a 3-year-old victim of noma, taken in hand;
- Acute-phase care for 5 months, with free health care and food;
- Treatment during surgical campaign of 2003;
- Social monitoring within the family, including medical, oral & dental supervision, food aid, various kinds of awareness-raising... until 2005;
- Preparation and transfer to Switzerland from March to August 2006;
- Taken in hand by Professor Brigitte Pittet of the University Hospital in Geneva (HUG) for two operations:
  - 1st operation to rebuild the cheek and nose with a free flap from the right latissimus dorsi and a skin graft taken from the scalp;
  - 2nd operation for commissuroplasty and tidying up of the flap;
- Return to Zinder until December 2006 for oral care and physiotherapy 3x per day, installation of a drain to be worn in the left nostril 24h/24h, regular cleaning, wearing of a brace 24h/24h, and massage of flap and scars with a fatty cream 3x per day;
- Regular physiotherapy treatment, frequent monitoring, surgical consultations, followed by schooling, and monitoring of the social assistance provided to the mother and father since 2007;
- In June 2012, Zeinabou's oral aperture is still stable and the mobility of her jaws acceptable;
- Present and Future Situation :
  - Medical Monitoring: Monitoring and consultations during regular HUG visits. Reconstruction of the lower eyelid and tidying up of nose still outstanding;
  - Educational monitoring: Zeinabou is in Year 2 of elementary school ;
  - Social monitoring: Social assistance (a financial loan) to the father, monitoring of repayments. Welfare assistance to mother, monitoring of their small business;
  - Frequency of visits: every 4 months

Manon concluded by noting that the security situation was deteriorating at an alarming rate, which had led in particular to the cancellation of the next Sentinelles surgical mission to Ouahigouya. Over the past 12 months, Sentinelles had found 17 new cases of noma in Niger and noted a resurgence of the disease in recent months, suggesting a very bad year in 2013. Through her, Sentinelles expressed their wish to know the number of children identified during the same period by other member associations that had similar programmes, so that everyone could have a better view of the overall situation.

#### **4. WHO Regional Program for the Fight against Noma**

##### **Cooperation agreement between WHO & Winds of Hope: Review and future prospects**

Philippe reminded everyone that the Regional Program to combat noma had been revived following the renewal of the cooperation agreement between WHO and Winds of Hope at the end of 2010. He gave the floor to Dr. Benoit Varenne, WHO / AFRO coordinator, to summarize the situation.

Benoit first explained that WHO was organized into six regions, with the African region comprising 46 states, i.e. the entire continent except for the six states located in the north-east.

He indicated that strengthening the regional program to fight Noma was currently one of the priorities of the WHO oral health program. Prevalence, morbidity and mortality are considered "high" among the lower socio-economic groups in the African Region of WHO.

Benoît then turned to the reactivation of the fight against noma in Benin, Burkina Faso, Mali, Niger, Togo and Senegal. Following signature in October 2010 of the new cooperation agreement, a new intervention strategy had been defined with Philippe:

- Annual National Action Plans
- Planning of access to results / Action Plans
- Coordination and communication
- Support for WHO's In-Country Offices
- Process for finalizing and validating plans
- Annual Inter-country Workshop

The 6 national action plans were developed on the basis of five components, which also constituted objectives:

- Strengthening and building of capabilities
- Early detection and immediate treatment of cases
- Advocacy and social mobilization
- Development of training and education materials
- Coordination, monitoring and evaluation

The Inter-country Workshop in Niamey, Niger, successfully pursued three objectives:

- Sharing experiences about the challenges and the approaches taken in the context of the re-launched program;
- Drawing up a consolidated balance-sheet of the activities carried out in the countries since 2003;
- Working on a 2011 action plan to fight against noma in each of the countries.

The key points in finalizing the 2011 national action plans were the following:

- Monitoring the implementation of directives;
- Inclusion of measurable results, together with relevant indicators;
- Justification of regions and population groups on which activities were targeted;
- Support missions for Mali, Senegal and Togo.

Implementation of the 2011 national action plans resulted, for example, in the following activities and results in two countries:

- **NIGER :**
  - Training of: 150 health workers in the regions of Maradi and Tillabéry ; 200 traditional healers in the Maradi and Tahoua areas ; 200 female points of contact and birth attendants in Maradi and Tahoua ; and 75 basic education organizers in the Tahoua region.
  - Oral-screening and noma-detection sessions in the CRENIs (Children's Recovery and Nutrition Centers) of Maradi, Tahoua and Zinder Tillabéry by dentists from the regions concerned - 764 children were diagnosed, including nine new cases of early noma;

- Advocacy and social mobilization, with 15 broadcasting contracts signed by the radio stations in the regions of Agadez, Diffa, Dosso, Maradi, Niamey, Tahoua and Tillabery; 11 interactive debates and 14 awareness-raising sessions, reaching 2,965 people.
- **BENIN :**
  - Training of: 80 head doctors and health area coordinators; 200 health workers (nurses, midwives, social workers) ; 200 community points-of-contact, 60 of whom were teachers, in the Atacora-Donga, Borgou-Alibori , Zou-Collines and Mono-Couffo departments;
  - Field tours for screening, information, education and advocacy, and the treatment of people with noma and oral diseases - 450 patients were seen and treated. The aim was to bring about change in people's behavior vis-à-vis noma risk factors, and to provide consultations and proper treatment for the populations in the places visited.

The inter-country workshop at Ouidah in Benin successfully tackled three specific objectives:

- Drawing up of a comprehensive critical review of the activities and achievements in 2011 in the six countries;
- Refining strategies for monitoring and supervision to be developed in the 2012 action plans;
- Exchanging experiences on the role and responsibilities devolved to community health workers in the fight against noma.

This last point allowed a common technical position to be adopted on a package of activities for Community Health Officers:

<b>FUNCTIONS</b>	<b>TASKS</b>
<b>Advice &amp; Preventive Checks</b>	<ul style="list-style-type: none"> <li>- Home visiting, door-to-door</li> <li>- Environmental hygiene advice</li> <li>- Advice on oral health</li> <li>- Dietary advice</li> <li>- Checks on children's growth-rates and psychomotor development</li> <li>- Monitoring of children's vaccination status, by checking vaccination certificates and questioning mothers</li> </ul>
<b>Raising of awareness about noma</b>	<ul style="list-style-type: none"> <li>- Facilitating educational talks on noma (definition, recognition of early signs, predisposing factors, prevention methods)</li> <li>- N.B. : with a nurse, depending on size of crowd</li> <li>- Broadcasting of messages about risk factors for noma during vaccination, weight monitoring and micronutrient distribution campaign days etc.</li> </ul>

<p><b>Early detection</b></p> <p><b>Active searching for cases</b></p>	<ul style="list-style-type: none"> <li>- Systematic inspection during home visits of the mouths of malnourished children under age six (breath, saliva, tooth decay, ulcers, inflammation, bleeding, gingivitis), using the tongue depressor provided.</li> <li>- Opening children's mouths, if possible using the tongue depressor, (to check breath, saliva, tooth decay, ulcers, inflammation, bleeding, gingivitis) every time that there is contact with children, especially during health campaign days (vaccination, weight monitoring, distribution of micronutrients, etc..).</li> <li>- Encouraging parents, especially mothers, to look into the mouths of their infants</li> <li>- Convincing parents to bring their children into the nearest health center if they have grounds for suspicion.</li> </ul>
<p><b>Referring cases</b></p>	<ul style="list-style-type: none"> <li>- Give the child a mouthwash with salt water, and teach the mother how to do this if noma is suspected, before referring the child.</li> <li>- Refer suspected cases of oral diseases</li> <li>- Refer cases of noma sequelae</li> <li>- Urgently refer all suspected cases of gingivitis, edema and new noma to the appropriate local facility</li> </ul>
<p><b>Patient monitoring</b></p>	<ul style="list-style-type: none"> <li>- Help parents, especially mothers, to observe the treatment.</li> <li>- Make sure that they administer it regularly</li> <li>- Make sure that referred cases are properly handled</li> </ul>
<p><b>Data Collection</b></p>	<ul style="list-style-type: none"> <li>- Notify all suspected cases of oral diseases</li> <li>- Urgently notify all suspected cases of gingivitis, edema and fresh noma</li> <li>- Notify cases of noma sequelae</li> <li>- Report on activities completed</li> </ul>

The components of the 2012-2013 National Action Plans were redefined to match resources, on the basis of experience gained:

- Developing capabilities of health and social services staff (35%)
- Building capability at community level (35%)
- Advocacy and social mobilization (15%)
- Development of educational and training materials (5%)
- National Coordination (5%)

Finally, Benoît outlined future prospects at various levels:

- National Coordination within countries :
  - Application of the package of activities against noma for community workers;
  - Adaptation and use of the monitoring card, and monitoring of national action plans;
  - Compliance with a timetable for finalizing action plans, and transmission of activity reports to WHO;
  - Use of common framework when drawing up activity reports;
  - Monitoring of training through in-field supervision, with grids for evaluating the knowledge and skills of staff trained;
  - Accelerating decentralization of training and supervision in the health areas of each country.
- WHO country offices :
  - Continued commitment to monitoring and supervision of planned activities in the field;
  - Production of a biannual progress report containing proposals for improving performance in national programs.
- WHO Regional Office, in collaboration with Winds of Hope :
  - Study conducted by WHO / AFRO on the methods and consequences of having noma included on the list of neglected tropical diseases ;
  - Search for new partners to support regional program components not supported under the agreement with Winds of Hope ;
  - Completion of a modification to the agreement in 2013 proposing solutions to the problems encountered with the 2010 agreement ;
  - Expansion of the number of beneficiary countries in the regional program for combating noma.

Benoît's presentation sparked a debate about the place that the NGOs and Associations in the Federation occupy in the implementation of national programs to fight noma. The goal is to find ways to capitalize on the leverage that would result from greater collaboration and coordination between NGOs and ministry noma departments.

Philippe confirmed Winds of Hope's desire to promote and strengthen these exchanges. In this context, the various associations are always invited to join in the discussions when a workshop is held in the country where they are active. To date, there have not been enough inter-country workshops organized to involve all stakeholders in the Federation, but the desire for greater collaboration is certainly there.

Several speakers, including Jean-Luc Eiselé (FDI), Marie-Claude Bottineau (MSF), Adama Sougouri (La Voix du Paysan) and Sady Kipasa (No to Noma in DRC) wondered what had led the WHO to treat noma as a tropical disease within the department of oral diseases, whereas noma, as a neglected disease, could have been made the responsibility of the existing dedicated department for such diseases.

Benoît explained that, given the current organization of WHO / AFRO, the current classification of noma allowed for better recognition and treatment of the disease.

**5. Gesnoma – Studies and Research on noma - no status report**

Dr. Denise Baratti-Mayer outlined the main elements of the study presented in 2010:

- Risk factors for noma: malnutrition, malaria, frequent pregnancies and acute necrotizing gingivitis (ANG)
- Outlook: The relationship between maternal malnutrition and noma, and the prevalence of ANG in villages with noma

This study, conducted between 2001 and 2006, together with an anthropological study, showed that:

- The average age of children affected was 3.7 years
- Certain neighboring villages that were apparently subject to the same environment seemed to be protected from noma, but others not.

Denise presented a new study on the state of oral health and the prevalence of ANG in children living in the Zinder region (Niger). The aim, by comparing villages with and without noma, was to determine whether there were any differences in oral hygiene and care of newborn babies in the two types of village. For this, four villages in the Zinder region, two with and two without noma, were targeted: Droum & Guidimouni and Wacha & Guidiguir. Between 100 and 120 children aged 2 to 6 years in each village were given a questionnaire as well as a general clinical examination (malnutrition, etc..) and an oral examination (for ANG and other lesions).

The goals of this new study were to:

- Conduct a descriptive epidemiological study of the oral health of children in selected villages;
- Determine the prevalence of ANG in the same region;
- Highlight differences in dental hygiene and prevalence of ANG in villages with and without noma;
- Highlight differences in the care of infants and during pregnancy in these villages.

Madibèlè Kam, from Hymne aux Enfants, said that whilst he did not underestimate the importance of birth order among siblings in relation to the amount of food each receives (the youngest being the least well provided for) he thought that the nutritional status of the mother was of paramount importance.

Marie-Claude Bottineau of MSF emphasized the need to include a systematic oral examination during inspections of malnourished children and to implement ANG screening during mass immunization campaigns. She reminded everyone that MSF supported CRENI and emergency pediatric practice with nutritional help.

A debate was also opened on how to define clearly the different stages of noma, following an intervention from Philippe on what he, from an operational, non-medical viewpoint, considered to be the three stages of noma:

- ANG, edema - the stage where the patient can still be saved
- fresh noma
- noma sequelae

Michel Poitevin, Aviation Sans Frontières, says that these three stages could be defined as primary, secondary and tertiary.

Manon explained the importance of oral inspections at the Sentinelles center in Zinder, so as to start treatment increasingly early, and so avoid loss of facial tissues.

Philippe stressed the importance of clearly defining the terms used by personnel in the field. At present, when a case of noma was identified, we had no way of knowing what stage of disease was meant.



Denise pointed out that, from a medical point of view, ANG was not yet noma. On the other hand, an ANG associated with edema can be considered an incipient noma. She considered that the term "developing noma" was probably the most appropriate to describe the intermediate phase, which lasts only a few days.

Sady Kipasa, from No to Noma in the DRC, said that ANGs that develop into noma give off a characteristic smell in the mouth.

Since this desire for clarification was shared by many members of the Federation, Benoit (WHO), Jean-Luc Eiselé (IDF) and Denise (GESNOMA) volunteered to work together to develop a document that would provide definitions consistent both with the state of medical science and with requirements in the field during campaigns of prevention and early detection.

Bernard Mivelaz of Persis Valais, asked whether it was possible to treat an ANG without visiting a dental office. The answer was that it was difficult or impossible to treat ANG without a visit to a suitably equipped surgery, whether permanently fixed or mobile.

Marie-Claude asked whether in cases of ANG, there should not be routine tests for HIV, even in countries like Niger where HIV is not so widespread. She noted that sometimes an ANG followed by an edema developed into noma despite antibiotic treatment, because of a HIV environment.

Priscilla Benner, of the MAMA Project, said there was a good database at the Esperium Foundation on the presence of minerals, flora and fauna in the noma areas.

Denise was unaware of this. Marie-Claude said that the presence of animal feces in children's lives had been discussed as a risk factor, but nothing significant had been found in the studies. Finally, Priscilla mentioned the website <[www.hesperian.org](http://www.hesperian.org)> of the Hesperian Foundation, from which a medical guide entitled "Where There is no Dentist", could be downloaded in English and French. This contained very useful information for nurses in the field, and it dealt with noma.

## **6. Noma-Hilfe-Schweiz – Activities and developments**

Gabriella Skala, responsible for supporting Claude Junker at Noma-Hilfe-Schweiz, said that the association was currently undergoing restructuring, both of its Council and its management. However, its main activity remained the offer of financial support to field work in the following areas:

- prevention and education: training of social workers, mothers and midwives
  - medical and surgical treatment : supporting patients and medical staff
  - rehabilitation and assistance: support for victims, their families and social workers
- Noma-Hilfe Schweiz collaborates with Hilfsaktion Noma in Niger and Guinea-Bissau as well as Persis in Burkina Faso.

Collaborative projects are underway with Interplast in Cameroon, Project Harar in Ethiopia and Physionoma in Niger and Burkina Faso.

**7. Project Harar – The burden of noma: myths, risk factors and medical responses**

Dr. Nadia Lafferty of the Liverpool School of Tropical Medicine, conducted a study in Harar in east-central Ethiopia at the initiative of the NGO Project Harar, represented by Tom Hoyle. The country in brief: 90 million inhabitants of whom 46% are under 15 years old - 38% live in absolute poverty - 43% literacy rate over age 15 - 20% live more than 10 km from a health outpost – 85% to 91% of population rural.

She explained the great difficulty of working in a country with 84 native dialects. Her work had focused on 39 cases of noma sequelae each of which had been the subject of an interview and clinical examination. The victims were aged between 10 and 50. Nine of them were under 16 years of age. 72% had contracted noma during their first 5 years of life.

The study found only a low incidence of noma in Ethiopia, but the very small number of cases studied did not allow generalization of the findings.

Denise noted that no new cases of noma were considered in this study. She asked if that meant that there had been no new cases recently identified, and if there was a known reason for this phenomenon.

Neither Nadia nor Tom had any specific evidence to explain this.

**8. Augustin Koara, Nurse at Maison de Fati – Material for raising awareness of noma**

A child victim of an ameloblastoma, Augustin Koara, a nurse at the Maison de Fati in Ouagadougou, was often required to treat children with noma and, as part of his duties, participated in many surgical missions involving them. Convinced of the need for campaigns of prevention and awareness-raising for noma, he had decided on his own initiative to use his passion for music to get his message across. With the help of friends, he had recorded songs that were broadcast by local radio stations, and made two clips that were shown on national television channels in Burkina Faso.

These works had been recorded in several languages, using traditional instruments. His initiative was supported by the Maison de Fati, Ensemble Pour Eux and Winds of Hope. The CD and the clips were offered for sale to members of the Federation for use in their prevention and advocacy campaigns. Philippe asked Caroline Benaim, President of Maison de Fati, to congratulate Augustin on his initiative, and he strongly urged members to make use of this valuable material.

## **Saturday 29 September**

The Round Table resumed at 9h00.

### **9. Introduction by the presidency**

A joyous start to the day ... members sang « Happy Birthday » to Tom Hoyle !

Philippe welcomed Bertrand Piccard, President of Winds of Hope, and his wife Michele, a member of the Council, who had been able to join the Assembly for the second day of its deliberations. He summarized for them the discussions of the previous day.

Bertrand thanked all members for their participation in the 11th Round Table and the durability of their commitment to the fight against noma. He explains that he, in turn, had had an opportunity to meet Princess Layla Salma of Morocco, and to discuss noma with her. Very moved by this affliction, she had offered to host 10 child noma sufferers per year in a Moroccan hospital, so that they could be operated on and receive the required pre-and post-operative care. He found this to be a particularly interesting proposal, in that it allowed an alternative solution for operating on children from countries where the security situation was increasingly hostile to the organization of surgical missions.

Philippe also welcomed Jean Ziegler, Vice-Chairman of the Advisory Council for Human Rights, and HE Vokouma Prosper, Ambassador of Burkina Faso to Switzerland and the UN in Geneva, who had just arrived.

Claire Pouteau of Physionoma requested the floor to report on their association's mission to Togo. The association had spent a week training therapists from Togo, Benin and Burkina Faso, so as to ensure on-site follow-up after surgical missions. Having now received the same training as in France, this local staff is able to provide treatment for post-operative rehabilitation for one year or more. Physionoma had found this to be a very rewarding experience, and the subsequent benefits particularly useful. She was therefore prepared to start similar training in other countries or hospitals.

Christine Allary of Enfants du Noma showed her interest, asking several questions, including on training programs and salaries.

### **10. Dutch Noma Foundation – Project in Cameroon**

Robert van Poppelen of the Dutch Noma Foundation reminded everyone of the announcement in 2011 that the NGO, which specialized in organizing surgical missions, had stopped their program in Nigeria after 16 years of activity in Sokoto. Two main reasons had caused this departure:

- Political instability and corruption that made for extremely difficult working conditions,
- The security situation, with an alarming increase in extremist groups such as Boko Haram, and the murder of two foreigners in Sokoto.

Since then, Dutch Noma had therefore been looking for a new country in which to conduct its fight against noma. Noting that many members of the Federation were present in Burkina Faso and Niger, the Foundation had decided to commit to countries where there was no, or hardly any humanitarian work in this field. It had studied applications received from Cameroon and Burundi. Having chosen Cameroon, the Foundation had made several visits to the country, in which it had carefully identified available facilities (hospital, surgical, post-operative care), infrastructure (for receiving patients and their families), and other logistical matters (medical practices, visas, importation of materials, government invitations).

Finally, of the four hospitals visited, Kumba was chosen, and as an initial project two surgical missions will be conducted there for Cameroonian patients. Robert explained that, by committing to Cameroon, Dutch Noma was intending to push back the boundaries of Noma in countries where patients had not yet received any help. They would also later welcome patients from Burundi and Nigeria. To do this, the Foundation was looking for funds and requested help from members of the Federation who wanted to contribute.

Bertrand recommended that Robert should contact Benoit's predecessor, Dr. Charlotte Faty Ndiaye who was the WHO representative in Cameroon and who could be of great assistance for the implementation of their project.

In the same spirit, Michel Poitevin, of Aviation Sans Frontières, wondered what was going on in Chad. Carole Ballanfat of Winds of Hope mentioned recent discussions with Médecins Sans Frontières, which was active in this country, especially through their large-scale nutritional program. They intended to export to Chad their pilot project for detection of noma, which was underway in collaboration with Sentinelles at Zinder in Niger. For the moment, the security situation in the country did not allow the necessary monitoring of children to take place.

#### **11. Winds of Hope – Noma Day**

Winds of Hope is considering organizing another Noma Day. Philippe wished to know which members were prepared to commit to a new edition. Once a decision was made whether or not to hold one, and if so when, he would contact everyone by email to form a working group.

#### **12. Winds of Hope / NoNoma Federation – Internet Sites**

The new website of Winds of Hope was being finalized and would be on-line by early 2013. Philippe briefly described the architecture of this new version, which would be much more up-to-date in technology, and whose content would report more fully on the work of the Foundation. He also reaffirmed the commitment of WoH to offer the Federation a new version of the NoNoma website, and opened a discussion about the purpose and content of the site required by members, as well as about the possible formation of a working group.

Laurence Alexandra Porchat of AEMV / GESNOMA proposed creating a blog. This would be interesting because of its flexibility, but a blog required a lot of time to manage, and Winds of Hope did not have the resources to do this. A simple Facebook page would act as a platform for rapid information exchange between members. It could also include a space where visitors to the site could post questions, requests or information, which would be relayed automatically by email to all members. It would then be up to stakeholders to respond, and for Winds of Hope to ensure that each intervention received a response.

Flavie Ott Physionoma, wondered if the site was more of a showcase for the general public, or a platform for exchange of information. Philippe replied that the site should remain a showcase of information for those interested in noma. As with most of our sites, there would be the following headings, amongst others:

News - The NoNoma Federation - Noma - Members

Under this last heading, each member would have a space containing its mission, its logo, a description of its activities, contact information, a link to its own site and links to, or imports of newsletters and activity reports. The information made available here would be the responsibility of each association. On the other hand, the level of critical and technical exchanges between members is not high enough to justify a dedicated platform. Email is perfectly adequate to fulfil this role.

In reply to a question from Michèle Piccard, Winds of Hope, Philippe replied that, as now, all members would have an access code that would allow them to upload information and reports onto the space reserved for them. He said that the NoNoma site would be constructed by Winds of Hope in two languages, French and English. However, each member would be responsible for translating its own material.

Robert asked if it might be possible to have a space for publishing scientific articles, forming a kind of bibliography. Philippe agreed to this. This raised the question of the validity and relevance of published information. Winds of Hope reserved the right to withdraw any publication that gave rise to well-founded objections from any member. It was common knowledge that sharing information meant exposing oneself to criticism, positive or negative. Gabriella Skala of Noma-Hilfe thought it was also important to have a common area for the general public to read the stories of our joint initiatives. It was also necessary to have a common definition of what we understood by noma and its phases.

Valerie Maeder of Ensemble Pour Eux said that not so many members would be prepared to volunteer, because their first priority was to maintain their own websites and Facebook pages. Adama Sougouri of La Voix du Paysan said that a website like this was very interesting for organizations that could not afford their own site. It offered them a small presence on the web.

Michele suggested that all the work done for Noma Day, suitably updated, should be uploaded onto the site. Philippe reassured her that this would be done. Jean-Luc brought the discussion to a successful conclusion by stressing that the site should reflect the values of the Federation. Philip reminded everyone of the high workload of renovating and managing a website, and the need for consensus on site architecture and the nature of the information to be posted. This implied the active participation of Federation members. He asked if any members were interested in the project and prepared to join a working group.

Noma-Hilfe (Gabriela Skala), FDI (Jean-Luc Eiselé), Hymne aux enfants (Mao Savadogo) and GESNOMA (Denise Baratti-Mayer) offered their services.

**13. Council for Human Rights –The fight against noma, a struggle for children’s human rights –  
Consequences of the adoption of the resolution**

Philippe welcomed the distinguished presence of HE Prosper Vokouma, Ambassador of Burkina Faso to Switzerland and the United Nations in Geneva, and of Jean Ziegler, Vice-Chairman of the Advisory Committee on Human Rights. He reiterated his sincere thanks for the decisive action taken by Jean Ziegler, supported by HE Prosper Vokouma. This had led to the adoption in March 2012 of a resolution that took noma as an emblematic disease and established a link between severe malnutrition and childhood diseases. The Human Rights Council had thus recognized noma as a marker of extreme poverty. Philippe reminded members of the considerable work that had been undertaken to achieve this result.

HE Prosper Vokouma in turn thanked Winds of Hope for the invitation and said that given the efforts made by the Foundation in the fight against noma, including program funding for the fight against Noma in his country, he considered it his duty to participate in the initiatives undertaken by the Foundation and the Federation to fight against this terrible scourge. The Ambassador said that the move to support the work of Jean Ziegler reflected a wish for political recognition of the problems associated with poverty in his country. Thus, Burkina Faso had recently supported three resolutions that particularly or exclusively affected the most disadvantaged populations, namely those on neo-natal mortality, female genital mutilation and noma.

Jean Ziegler in turn paid tribute to the work and influence of HE Prosper Vokouma, who had been truly committed and involved in this initiative, and without whom the resolution would not have been adopted. Jean Ziegler then proceeded to decode the UN language and explain clearly to members of the Federation the options that the adoption of the resolution had opened up, both in terms of advocacy and concrete action.

He recalled that the Human Rights Council is composed of 47 states and is the main intergovernmental body of the United Nations responsible for the promotion and protection of Human Rights. The Advisory Committee on Human Rights is, in turn, composed of 18 independent experts. Its main function is to undertake studies highlighting the difficulties faced by people located in regions that require the special attention of the Human Rights Council, such as breaches of the right to food.

In summary, the resolution, which was approved unanimously by the 47 countries representing 193 UN member states, identifies noma as a violation of the right to food, which itself is recognized and enshrined in the Universal Declaration of Human Rights of 1948 (Article 25). This recognition is also supported by the International Convention on the Rights of the Child.

Jean Ziegler emphasized that the Board periodically reviews the situation of human rights in each of the 193 UN member states. In practice, each signatory state must appear before a committee every 5 years for three or four days to report on compliance with its human rights obligations. This committee of 11 experts can call on civil society to check the veracity of statements made by the country’s representatives. This means that the Human Rights Council is the only UN agency that gives a voice to NGOs.

It is usually the country's ambassador who is received by the monitoring Committee. When a country is preparing its report, it may seek assistance from members of civil society and NGOs. To maximize this pressure on States, it is necessary to contact the monitoring Committee and urge them to ask questions relating to the State's commitment to the fight against noma during their five-yearly presentation. No State can appear before the monitoring committee of the Council and state that they have no noma in their country. The Human Rights Council has no enforcement mechanism but can issue standards and guidelines. However, in the United Nations system, there are very specific indirect sanctions for violations of human rights.

Noting skepticism in the room, Jean Ziegler stressed that since Kofi Annan's time, there had been a very clear decision establishing the primacy of human rights over all statutory and international laws. Even if there was indeed no formal obligation to comply with decisions taken by the Council there was, however, an effective constraint involving the World Bank or the International Monetary Fund. For example, when a state requests rescheduling of its debt, one of the conditions for acceptance of its case will be that its policy must comply with respect of international law in the field of human rights. Therefore, following adoption of the "resolution on noma", States must now account for progress on implementation of the measures they committed themselves to by voting for the resolution and its annex. The texts of these were distributed to the members at the meeting and there is a link to them on the [www.windsofhope.org](http://www.windsofhope.org) website.

HE Prosper Vokouma confirmed that, from the member States' point of view, things were starting to move. Even if these measures were initially perceived as new pressures or political conditions for credit, countries had resigned themselves to implementing them. For example, each state must now create a National Human Rights Commission. Civil society is also much more active than before and citizens are increasingly demanding.

Finally, Jean Ziegler gave special thanks to Winds of Hope, Médecins Sans Frontières, Sentinelles, the FDI and all organizations involved in the process that led to the adoption of "the resolution on noma" by the Council of Human Rights. He recommended always having this resolution and its annex to hand when having direct discussions with governments.

Bertrand Piccard thought that what had been achieved was absolutely amazing. He congratulated all those who had taken part in this work, with particular attention to Jean Ziegler and SE Prosper Vokouma, whom he designated as benefactors of the cause. He was pleased to note that noma had officially emerged from the shadows. This previously unknown and neglected disease had finally been legally recognized. This was a powerful weapon that we must now use. With this in mind, Bertrand recommended that all members of the Federation contact the Ministries of Health. HE Prosper Vokouma stressed that the countries' ambassadors should always be the first points of contact before going out into the field.

Bertrand believed that the human rights approach must be used to leverage advocacy against the disease. The acceptance of this resolution marked the end of an era where the stakeholders involved in the fight against noma were faced with a lack of recognition by international authorities. He added that we must now use this tool to denounce the problem and request that action be taken. We must put pressure on the governments that are affected by the scourge of noma but who deny its existence, by sending them photos of children affected by the disease. He stated that this action could be organized jointly by members of the Federation and that it was the role of WHO to maintain pressure.

Jean Ziegler added that it was important to approach the WHO to get noma recognized as a neglected disease. This would allow states to have access to credits for therapeutic measures. Benoit intervened, stating that it was also the role of WHO to make proposals to member states, raising issues and challenges in the field of health. This year, the WHO Regional Committee had discussed several issues including the issue of human rights, which will be included in the WHO Plan for 2014-2016.

Answering a question from Priscilla about "educating" Ministers of Health, HE Vokouma Prosper said that awareness had already been raised at this level. He explained that in his country, noma was not only a neglected disease, but also considered shameful, and prevention work is essential for sensitizing people. Bertrand added that we could help these countries to become more aware, and work to reduce the disease, rather than attacking them with needle-pricks. We need to circulate photos and reports to create a database providing irrefutable proof of the presence of Noma.

Sady Kipasa of No Noma DRC wondered if these guidelines were available in French so that they would be usable. Jean Ziegler replied that translations should be made into the seven official languages of the United Nations, but that took time.

#### **14. Security situation in Africa – exchange of information and experience.**

Mahmoudou Kassambara from the NGO Prometheus of Mopti asked to speak to the meeting, and delivered a poignant testimony on the situation in his region and in Mali as a whole. He described, not without emotion, the difficult situation to which the local population was exposed, "taken hostage" between the National Movement for the Liberation of Azawad and the Islamists, all leading to a dramatic increase in banditry. Activities were reducing and poverty setting in.

HE Vokouma Prosper testified that he had spent 3 days in the north of Burkina Faso to visit six Malian refugee camps, and to conduct some serious analysis of the situation. He said that there was currently no danger in travelling around, even in the northern regions where the Malian refugees were. Of course, the risk of a war of intervention in Mali by an international force could change the situation. He did not wish to pass judgment on the decision of Enfants du Noma to cancel three surgical missions, in compliance with the recommendations of the French Interior Ministry, but he encouraged NGOs to continue their activities in Burkina Faso, including the northern areas. The Ambassador wished to express his support for Dr. Zala Lassara's reception center, expressing his admiration for the doctor's great devotion and hard work. He assured everyone that he would issue visas free of charge to members carrying out humanitarian missions in his country, if they contacted him in Geneva.

Philippe Bédard of A Better Life Foundation announced that their local representative in Burkina Faso had three days previously received an email from the Minister of Territorial Administration warning all NGOs about their safety, given the crisis in Mali and the risk of kidnapping that stemmed from it. HE Prosper Vokouma reaffirmed that the situation was periodically reviewed, and that it was government's duty to pass on this information to diplomatic missions and NGOs. But he repeated that for towns like Ouahigouya, there was no risk. This did not mean that in such a context it was not wise to be especially vigilant.



Christine Allary of Enfants du Noma reflected with emotion on the reasons that had led them to cancel three surgical missions to Ouahigouya in Burkina Faso, but made clear that they would carry out nine missions to Ouagadougou in late 2012 and 2013.

Philippe stated that humanitarian work in the field with zero risk did not exist. The question that each individual had to face up to personally was what level of risk they were willing to face. The answer is a personal matter for each individual, and should not be a cause of judgment by others.

Philippe thanked HE Prosper Vokouma, Jean Ziegler, and Bertrand & Michèle Piccard for their prominent contributions to the proceedings of this second day. He paid tribute to all the participants for the quality and richness of the debates that had marked these two mornings. Finally, he expressed his gratitude to our simultaneous interpreter Tamara Pelège, our session secretaries, Arianne Vuagniaux and Marie Renaud, and our chief organizer, Carole Ballanfat

He wished everyone a safe journey home and looked forward to seeing them again the following year.

The Round Table was adjourned at 1:00 p.m.

Presidency :



Winds of Hope

Lausanne

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