

**Minutes
of the 16th Round Table
held on November 19th, 2020
online**

Presents

Presidency : Winds of Hope (WoH).

20 Active Members : Association d'Entraide des Mutilés du Visage (AEMV), Au Fil de la Vie (AFV), Avec Mali / Jura, Aviation sans Frontières (ASF), Bilifou-Bilifou, Facing Africa, Gegen Noma, Gesnoma, Hilfsaktion Noma e.V., Hymne aux enfants, Idées'Elles, La Voix du Paysan, Label Vert, Mamma Project, Noma-Hilfe Schweiz (NHS), Persis Valais, PhysioNoma, Sentinelles, Vaincre Noma, Winds of Hope (WoH).

1 Partner Member : La Chaîne de l'Espoir

0 Associate member

2 Candidates : Médecins sans Frontière (MSF), Cheira

9 Guests : Inediz (Claire Jeantet, réalisatrice Restoring Dignity), Noma Fund (Georges Nko'Ayissi, Linda Zaki). Membres du projet SNIS (Ioana Cismas, Marie-Solène Adamou Moussa Pham, Mirko Winkler, Prof. Emmanuel Kabengele). Joel Rosenbloom (Staff dentist, Assistant Professor Addis Abeba University Ethiopia), Dina Hanot (Présidente Regard Peuples et Nature)

Simultaneous Traduction

Marianne Wanstall

Francis Poulet

Apologies

3 Active Members : Ensemble pour Eux (EPE), Kasnoma, La Maison de Fati

0 Partner Member

0 Associate Member

Philippe Rathle opened the 16th Round Table of the International NoNoma Federation at 2:45pm.

A topic, including concerns expressed by members, the presentation of a research project and the screening of an MSF film on noma are on the agenda :

1. Insecurity and the pandemic : update and situation
2. Presentation of the SNIS research project
3. "Restoring dignity" produced by Inediz for MSF

1. Insecurity and the pandemic : update

The floor was given to the Assembly.

Sentinelles (Valérie Elsig) pointed out that these two issues are concurrent in all the countries they visit. They have great difficulty in confirming and organising missions. They would like to be able to share all this information, especially for surgical missions. The aim would really be to improve, share and communicate about these missions and to pool forces. They therefore propose to set up a communication channel.

Bilifou Bilifou (André Bühler) intervened to say that Persis in Ouahigouya is available to host missions.

Winds of Hope (Philippe Rathle) reminds us that Ouahigouya is in a red zone and therefore represents a certain danger to go there. It is a personal choice of risk tolerance.

La Chaîne de l'Espoir (Kevin Ninkeu) confirms that they organise missions to Burkina Faso in collaboration with Sentinelles and La Voix du Paysan. Insecurity is forcing them to review their mode of operation. It is therefore necessary to change the format, to arrive with smaller teams,

**Minutes
of the 16th Round Table
held on November 19th, 2020
online**

sometimes limited to one person. By working to redefine the operating mode, they are preparing to organise a mission in mid-December with just one person from France, but giving more room to Burkinabe surgeons, who have been accompanied and trained over the course of the missions they have organised. Constrained by the situation, they are going to accelerate this process and rely much more on local teams.

For example, in Mali, La Chaîne de l'Espoir organised a mission and Prof Olivier Baron left during the first days of the mission to see and give his opinion on the diagnoses and returned before the end of the mission. Thus the Malian team was able to complete the mission and manage the operations for about 50 people. La Chaîne de l'Espoir intervenes in capital cities such as Bamako in Mali or Ouagadougou in Burkina Faso for greater security. Interventions in Ouahigouya in Burkina Faso or in the rest of Mali are increasingly discouraged by officials. As Philippe said, the organisation of these missions depends on the will of the people and this raises discussions within Chaîne de l'Espoir which cannot imagine sending people who are not trained or not informed of the situation.

Philippe thanks Kevin for this intervention and asks him if Chaîne de l'Espoir has recently intervened in Niamey in Niger. Kévin replied in the negative.

Au Fil de la Vie (Sylvie Pialoux) would like to know the dates of the Chaîne de l'Espoir missions to Bamako as they have not been communicated to the various parties likely to bring noma patients. It seems to her that it is a good thing to have local surgeons working, but their interventions seem to her to be very limited. For example, cleft lips are covered but palates seem more complicated. In addition, patient follow-up is very complicated because there is sometimes no feedback. A link is made between Sylvie and Kévin. Kévin will put her in contact with the team in Mali.

All the participants seem to agree that mission reports are often difficult to obtain, as they depend very much on the will of those involved.

Philippe reminded the meeting that this is one of the Federation's mission, to strengthen communication between members.

Kevin confirmed the importance of improving communication before and after missions. He noted that Sylvie had raised the recurring point that mission reports depend a lot on the personal will of the people who lead the missions, but also for reasons of availability and organisation. Everyone must be aware of this and take decisions to move in this direction.

Philippe points out that you don't blow the bugle to announce your arrival. One of the basic rules of safety is not to shout too loudly that you are coming. He suggested that one should consult the Federation's website with its list of members. When organising a mission, you can simply point to the associations active in the region and contact them directly.

In this context, Valerie returned to her initial request. She wondered how to communicate better as a network, perhaps with an intranet via the website, in a secure and targeted manner, particularly so as not to forget anyone in our communications.

Philippe took note of this proposal, recalling that the Federation's website is mainly an information site. Making it a communication platform is a different matter from a technical and financial point of view. Winds of Hope will think about it and try to find a solution. Contributions from members are welcome.

The Association d'Entraide des Mutilés du Visage (AEMV - Brigitte Pittet) took the floor to talk about what happens at the HUG in Geneva. They carry out their missions with a team of

**Minutes
of the 16th Round Table
held on November 19th, 2020
online**

paediatric anaesthetists specialised in these endo-buccal operations and for them it is a question of safety to have qualified people. The corollary is that they are hospital staff and they are not allowed to take them to risk areas. As they can no longer take them to Mali or Burkina Faso, they now go to Dakar where there is a plastic surgery department run by Prof. Sankalé who is a fully trained plastic surgeon who is trying to develop her department specialising in plastic surgery. A visit in March enabled them to see noma patients from Dakar, sometimes after 15 years, and to operate on several pathologies. The skills of their anaesthetists are extremely important to enable them to intervene in the most serious cases. Patients from other countries can be transferred to Dakar without any problem, but follow-up is complicated, especially for cases that require several operations.

Bilifou Bilifou (André Bühler) informed the Assembly that the spirulina farm in Ouahigouya is fully operational and called on members to contact him to organise deliveries. He also recalled the usefulness of spirulina in a renutrition programme.

Aviation Sans Frontières (Michel Poitevin) reminded the Assembly that the ASFF was available and that members could make requests to the ASF to transport people and equipment.

2. SNIS research project

Marie-Solène presented the SNIS project to the Assembly : "Noma, the neglected disease. An interdisciplinary exploration of its reality, its burden and its framing". You will find the presentation sheet in the annex of these minutes and on the website at : www.thenomaproject.org.

During the ensuing discussion, ASF (Michel Poitevin) asked why the study focused on West African countries or Laos, when cases also exist in Madagascar and other African countries. Marie-Solène replied that the database provided by Sentinelles is extremely rich and well documented in these two regions. For this research work, they use this data, which does not exclude extending it to other countries.

3. Screening of "Restoring Dignity"

Philippe recalls the screening in front of the Assembly, two years earlier of the film "A visage découvert", by Hervé Pfister and Marie-Lou Dumauthioz. Here is another film, "Restoring Dignity" directed and produced by Inediz (Claire Jeantet) for Médecins sans Frontières. It was filmed in Sokoto, Nigeria and recently won an award.

All the information about it is available on the website : <https://www.restoring-dignity.com> including a short film which can be found at : <https://youtu.be/Mk8cHM9BBXo>. Members are encouraged to share it on their networks.

Philippe Rathle declared this Round Table closed at 6:30 pm and thanked the Assembly for its special participation this year.

The Chair :



Winds of Hope
Lausanne, December 19th, 2020