

**Minutes of the
16th General Assembly
November 19th, 2020
online**

Present

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 translation

Marianne Wanstall

Francis Poulet

Apologies with proxy

0 Active members

Apologies

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

0 Partner member

0 Associate member

Philippe Rathle, Director of Winds of Hope, noted that this was a first for the International NoNoma Federation, holding an entirely online meeting with more than fifty participants, necessitated by the context of the pandemic that will hit us in 2020.

He expressed his warmest thanks to Médecins sans Frontières (MSF) and their representative Mark Sherlock, MSF Health officer in Nigeria, and Claire Jeantet and Fabrice Catérini from the communication company Inediz, MSF without whom this meeting would have been simply impossible to organise. A special and warm mention to Claire for all the help she has given us with great competence and enthusiasm.

Philippe Rahtle declared the 16th General Assembly of the International NoNoma Federation open at 13:30.

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Philippe welcomed the presence of the two founders of the Nonoma Federation, Bertrand Piccard and Brian Jones. He noted the great honour of having them with us for the first time since 2004 and gave them the floor.

The founder of the Federation and President of Winds of Hope, Bertrand Piccard, addressed a few words of encouragement and congratulations to the members for their commitment and their constant motivation to move forward our cause.

A few words from Bertrand Piccard :

Although Noma is an important cause, Bertrand cannot devote as much time to it as he would like because his time is taken up by the Solar Impulse Foundation and the environmental issues that concern it. He is counting on the commitment of Philippe and Valérie Grand, our new secretary to the Foundation.

He notes that in these times of war, terrorism, jihadism and local political instabilities, the NoNoma Federation is even more necessary than before, despite the difficulty of the work and the security that is no longer guaranteed in these places. With links to governments broken, field work must continue as much as possible, as well as lobbying from where we are.

When the Federation was created, we had small associations that were very specialized in the noma cause, and then over time we have had larger organizations such as Mercy Ships, Chaîne de l'Espoir and MSF that have already participated in several of our meetings. It is a huge advantage to have them with us because it shows that noma is a much more global problem than we think.

As Jean Ziegler has ensured that noma is seen as an infringement of human rights in terms of the right to nutrition and health, the current major objective will be to get noma on the WHO list of Neglected Tropical Diseases. The reinforcement of MSF should give us more weight in this fight.

Everybody should know about NOMA but sometimes people open their eyes when they hear about it, so we have to work closely together to join forces in our work and also in the field of research. I wish you a good afternoon and a nice round table and I call on all of us to work together against noma also to make our voice heard.

Brian Jones now thanks Marianne Wanstall for her simultaneous translation. He was happy to see this old friends again, to discover new ones and to realise the legacy of those years when, together with Bertrand, the worked against noma and founded this Federation.

1. Introduction and presentation of participants

As a number of participants were present for the first time, Philippe Rathel briefly introduced each participant present including the guests :

- The SNIS study team, who will present the first results of their interdisciplinary exploration of the reality, burden and setting of the neglected disease noma in the following round table. It is represented by Marie-Solène Pham, Ioana Cismas, Dr Denise Baratti-Mayer, Prof. Emmanuel Kabengele and Mirko Winkler.

- The Noma Fund association, a very young organisation represented by Dr Georges Nko'Ayissi and Linda Zaki, Head of Communication. It is an initiative launched by two former football stars in the 1980s, Roger Milla and Joseph Antoine Bell, to act against noma, first in Cameroon and then in neighbouring countries. It provides for a major awareness raising and mobilisation plan, as well as the establishment of structures for the rapid care and reintegration of noma victims.

- Joel Rosenbloom, Canadian Dentist, Lecturer at the University of Toronto who has extensive experience working and teaching in Sudan, Mozambique and Ethiopia. He has been involved in attempts to have noma listed as a neglected tropical disease. He also published an interesting article on noma in the summer of 2020 which you all received with the invitation to this session.

- The Association Regard Peuples et Nature represented by Dina Hanot, its president, recently published an article in support of Winds of Hope, which also mentions the International NoNoma Federation.

Philippe Rathel notes the presence of 20 active members, 1 partner members, and 2 candidates, represented by 34 people.

With 13 guests, this assembly brings together 47 participants united in the fight against noma.

2. New Members

Médecins sans Frontières represented by Mark Sherlock, Health officer for Nigeria

A presentation of their actions had been sent to the members and Mark Sherlock was given the floor to say a few words.

MSF's application was accepted unanimously (20 in favour, 0 against, 0 abstentions).

Cheira, represented by Astrid Bergrundthal, Head of Missions

The activity report for 2019 had been sent to the members and Astrid was given the floor to say a few words.

Cheira's application was accepted unanimously (20 in favour, 0 against, 0 abstention).

The International NoNoma Federation wishes them a warm welcome.

3. Miscellaneous and closing

Philippe shared with everyone his deep appreciation and admiration for Marianne Wanstall, who has been providing the simultaneous of our meetings every year since 2009 with enthusiasm and loyalty. She is now brilliantly taking up the challenge of the technological leap of translation by videoconference !

He also thanks MSF for providing a second translator, Francis Poulet, to whom he expressed his gratitude.

Philippe returned to the discussion on the future of the Federation's round tables. The project that was to be set up with an alternation every other year between the Geneva Health Forum and Winds of Hope has been the facto frozen by the current pandemic situation but by no means abandoned. This subject will of course be put back on the table for discussion when the current situation returns to noma.

Philippe Rathle gave the floor to Michèle Piccard, member of the Winds of Hope Board.

She expressed her pleasure at seeing the faces that we have known for 20 years, because it means that they have not become discouraged despite the magnitude of the task, because the road is difficult, but there has been progress. The prevention, detection and training programs have had resonance and it is even more necessary to continue this path.

She thanked MSF for watching this magnificent film because one can measure their suffering and the importance of giving them some dignity. She noted that, despite periods such as the present one, which see an increase in cases, everyone is doing an extraordinary job. We all need to continue with real faith in what we are doing so that every person on this earth can live with dignity.

She thanked to organisers of this meeting which was very enriching and also a springboard to help us continue.

As no one else wished to speak on this subject, Philippe Rathle declared this General Assembly closed at 2:30 p.m. and thanked all the participant for this special edition.

For the Chair :



Winds of Hope
Lausanne, November 19th, 2020