

Presents

Presidency : Winds of Hope (WoH)

15 Active members : Association d'Entraide aux Mutilés du Visage (AEMV), Bilifou-Bilifou, Ensemble pour eux (EPE), Gegen Noma, Gesnoma, Hilfsaktion Noma e.V, Hymne aux Enfants, Label Vert, Médecins Sans Frontières (MSF), Noma-Hilfe Schweiz, (NHS), Persis Burkina, Persis Valais, Sentinelles, Voix du Paysan, Winds of Hope.

1 Partner member : Chaîne de l'Espoir.

1 Candidate : Fondation Gertrude Hirzel.

6 Guests : Isabelle Wachsmuth, l'équipe SNIS : Dr Denise Baratti-Mayer, Dr Iona Cismas, Anaïs Galli et Nora Monnier), Dirk Engels, ancien directeur des NTD à l'OMS, Dr Gabriel Alcoba, Coordinateur NTD aux HUG, Dr Bukola Oluyide (MSF), Claire Jeantet (MSF), Hervé Pfister (A visage découvert, réalisateur)

Apologies

10 Active members : Antenna Technologies, Au fil de la vie (AFV), Avec Mali-Jura, Aviation sans Frontières (ASF), Cheira, Enfants du Noma, Idées'Elles, Kasnoma, PhysioNoma, Vaincre Noma,

Absents

7 Active members : Facing Africa, Gigip, Maison de Fati, Mamma Project, Non au Noma en RDC, Peter Ustinov Foundation, Project Harar.

1 Partner member : Mercy Ships,

3 Associate member : Centre Nopoko, New Face, Prométhée

Philippe introduced the two topics of the afternoon lectures. Namely "Noma, The Neglected Disease. An Interdisciplinary Exploration of Its Realities, Burden and Framing" by Dr. Denise Baratti-Mayer, Dr Ioana Cismas and Nora Monnier.

The second presentation is entitled "Inclusion of noma in the WHO list of neglected tropical diseases" by Claire Jeantet and Dr Bukola Oluyide.

You all received the minutes of our last Round Table by email last Thursday, which will also be available on the Winds of Hope and NoNoma websites. There being no comments, we will proceed directly to the vote. The minutes of the 16th Round Table were then approved unanimously by the members present.

He declared open the 17th Round Table, which would follow throughout the day devoted to the fight against noma.

Presentation of the final results of the SNIS study :

Philippe introduced the presentation; this study is a big contribution to the truth about noma. The goal we all have in common is to be recognised by the WHO, this is an important goal and this study gives us one of the tools to achieve this goal..

Philippe introduit la présentation; cette étude est une grosse contribution à la vérité sur le noma. L'objectif que nous avons tous en commun est d'arriver à être reconnu par l'OMS, c'est un objectif important et cette étude nous donne l'un des outils nécessaires à la poursuite de cet objectif.

« *Noma, The Neglected Disease. An Interdisciplinary Exploration of Its Realities, Burden and Framing* »

« *Noma, La Maladie négligée. Une Exploration interdisciplinaire de sa réalité, de son fardeau et de sa formulation* »

par Dr Denise Baratti-Mayer, Dr Ioana Cismas and Nora Monnier.

Dr Ioana Cismas, Centre for Applied Human Rights, University of York
Overview of the SNIS project

**Neglected tropical diseases and human rights:
Effective paths for noma advocacy**

This presentation was done in english.

Dr Denise Baratti-Mayer, Institut de Santé Globale, Université de Genève
Risk factors and social determinants of noma: A retrospective study

This presentation was done in french

Nora Monnier, Swiss Tropical and Public Health Institute, Basel

Looking for the face of poverty:

A systematic literature review about the epidemiology of noma

This presentation was made in english.

The presentation of the SNIS being now over, the floor is given to Claire Jeantet who will first give us an update on MSF's work for the inscription of noma on the WHO list, followed by a debate with some participants.

"Noma on the WHO list of neglected tropical diseases"

by Claire Jeantet (MSF) and Dr Bukola Oluyide (MSF), followed d'un Q&A session

Bertrand congratulates and warmly encourages this approach. The first great pioneer was Edmond Kaiser who succeeded in raising awareness of these issues, but raising awareness is still very difficult. He believes that we must now stop being pioneers and ensure that the WHO becomes aware of this scourge and adds it to the list of neglected tropical diseases.

Following her presentation Claire leads a round table discussion with the participation of :

- Dirk Engels, director of NTDs at WHO until 2017, retired.
- Dr Gabriel Alcoba, coordinator NTD working group at HUG.
- Isabelle Wachsmuth, ancient member of WHO
- Philippe Rathle, director at Winds of Hope
- Dr Bukola Oluyide, MSF
- Claire Jeantet, Noma Campaign manager for MSF

IW (WHO) : We now need to consider an holistic approach although it is still important to continue to raise awareness.

DE (ex-WHO) : He is providing assistance and expertise in building the case. He has himself submitted a dossier on snakebites and highlights the excellent arguments for noma to be added to the list.

CJ (MSF) : Nigeria has taken the lead on this issue. We set a letter to Alain Berset, then Minister of Health. We need their commitment, by signing a letter. We invite everyone to use their diplomatic relations to get as many letters as possible. The African branch of the WHO is also involved in this process.

DE (ex-WHO) : Underlines the quality of the dossier, it is now the responsibility of WHO, it is important to say so.

BP (WoH) : Might be interested to know which country accepts and which country refuses or hesitates to sign these letters.

CJ (MSF) : mentionned that there is not really a refusal, but a lack of awareness, she explained that committing funds is not mandatory, and also had to explain what is expected from signatories. Sometimes the answers are simply that it is a non-existent disease in the country. It is important to focus on this.

Arianne (Label Vert) : What could help ? That my NGO writes to the Ministry of Health in my country ?

CJ (MSF) : Yes, there are letters, templates, she encourages forming teams and getting together.

DE (ex-WHO) : Suggests getting in touch with the World Food Bank too.

IW (WHO) : stresses that this is the right time to act, after the pandemic which slowed everything down and also that new people have arrived and have a real interest in noma.

Screening of the film "A visage découvert", followed by a Q&A
by Hervé Pfister and Marie-Lou Dumauthioz

In 2018, the Sentinelles Foundation entrusted Hervé Pfister and Marie-Lou Dumauthioz, with the task of making a documentary on children affected by noma in Burkina Faso. They travelled to Ouagadougou to the Sentinelles centre for a month in order to immerse themselves in the daily life of the people who fight this disease every day with children waiting for an operation and others in the recovery phase. Hervé and Marie-Lou wanted to show their daily life, their struggle, their hopes and their vision. They will also follow two little girls who were taken to the HUG in Geneva for surgery and film their journey through the healing process after their operation. Their documentary interweaves the testimonies of children, parents, surgeons and Sentinelles volunteers.

Screening of the film "Restoring Dignity"
by Claire Jeantet and Fabrice Catérini (Inediz)

In 2020, Claire Jeantet of Inediz directed and produced a documentary for Médecins Sans Frontières which was shot in Sokoto, Nigeria. It won an award that year.

Sakina is a little girl, Amina and Adamu are teenagers and Mulikat and Aliyu are adults who have lived for decades with the terrible physical and psychological consequences of noma. Coming from different parts of Nigeria, they found a unique hospital in the northwestern city of Sokoto to treat their wounds. While suffering pain, discomfort and discrimination, they embark on a life-changing journey to overcome years of isolation. "Restoring Dignity" offers a glimpse into the lives of the survivors and follows their struggles and successes over the course of a year.

All information is available on their website :
<https://www.restoring-dignity.com>.

Members were encouraged to share it on their networks.

Philippe declared this Round Table closed at 18:00 and thanked the meeting for its participation.

The Chair :



Winds of Hope
Lausanne, December 12th, 2022