

\* Event accessible in English and French \*  
\* Événement accessible en anglais et en français \*

# NOMA, A DISEASE THAT SHOULDN'T EXIST ANYMORE

#ZeroNoma #BeatNTDs

An online conference to raise the profile of a neglected disease

---

**PLEASE REGISTER TO JOIN**

**[WWW.HOPIN.TO/EVENTS/NOMA-CONFERENCE](http://WWW.HOPIN.TO/EVENTS/NOMA-CONFERENCE)**

---

Health systems are facing many challenges globally. Some, like Covid-19, receive massive attention from media, research institutes and policy makers, while other diseases which have been around for centuries remain neglected. One of these is noma and we believe it's possible to tackle it by increasing awareness.

This online event is designed for the global Neglected Tropical Diseases (NTDs) community: researchers, medical practitioners, donors, health focused humanitarian and development organisations, and UN representatives. It is organised by **Médecins Sans Frontières (MSF)** in partnership with the **International Society for Neglected Tropical Diseases (ISNTD)**, **Winds of Hope** / **International NoNoma Federation** and **Inediz**.

*Drawing of Sufyanu by Chloé Fournier / Inediz*

## THURSDAY FEBRUARY 11<sup>th</sup> 2021

12:00 - 16:00 UTC

**Welcome & host** - Marianne Comparet (ISNTD Director and Co-founder)

---

### 12:00 - PART 1: WHAT IS NOMA?

---

#### Surviving noma

Short documentary directed by Claire Jeantet and Fabrice Catérini - Inediz

Short message

#### **Prof. Peter Hotez - PLOS founding Editor-in-Chief / Baylor College of Medicine**

PLOS NTDs recently added noma to its own list of Neglected Tropical Diseases. Prof. Peter Hotez explains why prioritising this disease in the time of COVID-19.

Fidel's story

#### **Fidel Strub - Noma advocate and President of Noma-Aid Switzerland**

Following 27 surgeries and years of speech therapy, noma survivor and advocate Fidel Strub is active in efforts to overcome noma, here he shares his story.

What we know and don't know about noma

#### **Dr Denise Baratti-Mayer - Principal Member of 'The Noma Project'**

Noma expert Dr Denise Baratti-Mayer, outlines current clinical understanding of the disease, its prevalence and aetiology, and outstanding gaps.

---

### 12:30 - PART 2: A GLOBAL ISSUE

---

Short message

#### **Dr Osagie Ehanire - The Honourable Minister of Health, Federal Ministry of Health, Nigeria**

Hon. Dr Osagie Ehanire outlines the steps in place to increase awareness of noma in Nigeria and pledges the country's support to efforts to eradicate it.

A story about noma, an old companion of mankind

#### **Dr Klaas W. Marck - Plastic surgeon and Chairman of the former Dutch Noma Foundation**

Dr Klaas Marck looks at the history of noma, including how the disease disappeared from Europe in the 19th century and explains how we can tackle it today.

The hidden face of noma in Laos

#### **Dr Leila Srour - Pediatrician and Principal Member of 'The Noma Project'**

From Lao's first reported noma case to identifying over 50 survivors, Dr Leila Srour details the positive impact of clinical care on psychosocial wellbeing.

Update from Burkina Faso

#### **Dr Rose Drabo - Head of the Oral Health Department and the National Noma Control Programme, Ministry of Health, Burkina Faso**

Dr Rose Drabo provides an update about the National Noma Control Programme in Burkina Faso and the prevalence of the disease in the country.

---

### PANEL DISCUSSION 1

---

BREAK

---

---

### 13:30 - PART 3: THE BURDEN OF NOMA

---

Short message

**Dr Bertrand Piccard - Co-founder of the International NoNoma Federation, Psychiatrist, Explorer and Chairman of the Solar Impulse Foundation**

Dr Bertrand Piccard recounts his first experience with noma and shares his recommendations for the way forward to achieve global recognition for noma.

Mulikat's story

**Mulikat Okanlawon - Noma advocate and Hygiene Officer at the Noma Hospital in Sokoto**

Twenty years ago, Mulikat Okanlawon went to Sokoto (Nigeria) seeking medical care. She now works with other noma survivors and shares a message of hope.

Noma: burden, realities and framing

**Dr Ioana Cismas - Project Co-coordinator 'The Noma Project' / York Law School & Centre for Applied Human Rights**

Dr Ioana Cismas presents preliminary results of the study 'Noma, The Neglected Disease. An Interdisciplinary Exploration of Its Realities, Burden, and Framing.'

---

### PANEL DISCUSSION 2

---

BREAK

---

### 14:40 - PART 4: PREVENTING & TREATING

---

Short message

**Dr Christos Christou - International President of Médecins Sans Frontières (MSF)**

Dr Christos Christou, International President of MSF, explains the need for a patient-centred approach and calls on the WHO to include noma in its list of NTDs.

The holistic approach of MSF

**Dr Bukola Oluyide - Deputy Medical Coordinator Nigeria, Médecins Sans Frontières (MSF)**

Dr Bukola Oluyide describes MSF's holistic approach to supporting noma patients and the Sokoto Noma Hospital, run by the Nigerian Ministry of Health.

The challenges of reconstructive surgery

**Dr Issa Hamady - Plastic surgeon and Medical Director of the Noma Hospital in Niamey, Niger, Hilfsaktion Noma e.V.**

Collaborating with pioneers in the field for more than twenty years, Dr Issa Hamady explains the specific challenges of facial reconstruction for noma patients.

Chronological perspective of the WHO approach in the fight against noma

**Dr Yuka Makino - Technical Officer, World Health Organization Regional Office for Africa**

Dr Yuka Makino recounts global and regional milestones of WHO action in efforts to tackle noma, since its recognition as a public health issue in 1994.

---

### PANEL DISCUSSION 3

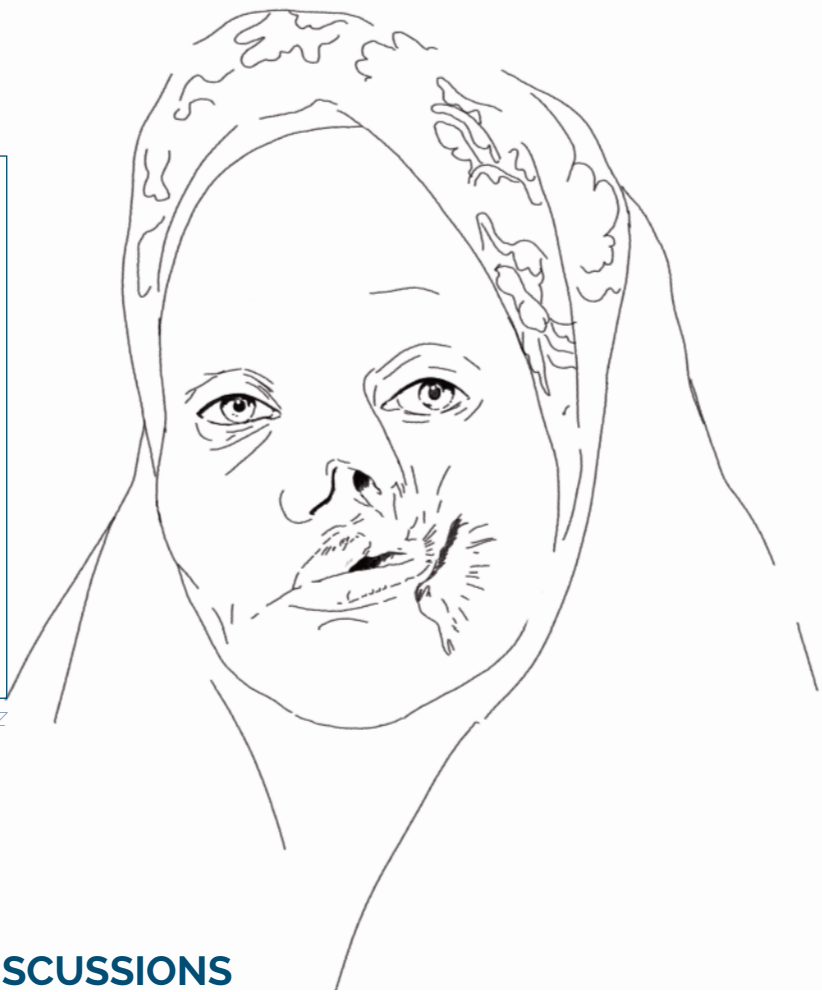
---

## NETWORKING

You can **start now** to use the networking options on the Hopin platform to connect with other participants:

- \* Please **create your profile**, and tell us about your interest in noma
  - \* Engage with different participants, using the main chat or private messages
  - \* Follow speakers and attendees on Twitter and connect on LinkedIn
- All networking options will be available until **4:10pm**, of February 11<sup>th</sup>, 2021.

*Drawing of Balkisu by Chloé Fournier / Inediz*



## PANEL DISCUSSIONS

Please share your questions in advance on social media using the hashtags

**#ZeroNoma #BeatNTDs**

---

**Session 1 - Eradicating noma through SDGs and the 2030 NTD roadmap**  
with Dr Julian Fisher (Researcher, Charité-Universitätsmedizin)  
and Kamran Rafiq (ISNTD Co-Founder & Communications Director)

---

**Session 2 - Neglected among the neglected: the paradox of noma**  
with Prof. Emmanuel Kabengele Mpinga (Project Coordinator 'The Noma Project')  
and Dr Ioana Cismas (Project Co-coordinator 'The Noma Project')

---

**Session 3 - The way forward to prevent and treat in the time of COVID-19**  
with Dr Mohana Amirtharajah (Surgery Advisor, MSF)  
and Mathis Winkler (Head of Projects, Hilfsaktion Noma e.V.)

---

\* All panel discussions will be hosted in the 'Sessions' tab  
and will be translated live into French in the chat \*

## MAIN CONTACTS

Claire Jeantet - Conference Organiser - [claire@inediz.com](mailto:claire@inediz.com)

Corinne Grant - MSF Communications Coordinator - [corinne.grant@amsterdam.msf.org](mailto:corinne.grant@amsterdam.msf.org)

Marianne Comparet - ISNTD Director - [comparetm@isntd.org](mailto:comparetm@isntd.org)