An online conference to raise the profile of a neglected disease

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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 11th 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
NOMA, A DISEASE THAT SHOULDN'T EXIST ANYMORE
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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 11th, 2021.

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
Corinne Grant - MSF Communications Coordinator - corinne.grant@amsterdam.msf.org
Marianne Comparet - ISNTD Director - comparetm@isntd.org