



## NEGLECTED TROPICAL DISEASE NGO NETWORK

A global forum for nongovernmental organizations  
working together on NTDs

# Schistosomiasis and Soil Transmitted Helminth NGDO Coordination Group A Disease-Specific Group of the NTD NGO Network

## TERMS OF REFERENCE

### 1. Background

The Schistosomiasis (SCH) and Soil Transmitted Helminth (STH) Non-Government and Developmental Organization (NGDO) Coordination Group was established in 2010 under the auspices of the NTD NGO Network (NNN), following the desire on the part of NGDO stakeholders engaged on these two diseases to share information and identify synergistic opportunities in their control. SCH and STH are often co-endemic and treatments are often delivered, and sometimes co-administered, using appropriate drug delivery platforms, such as school-based deworming mechanisms. They are also linked by key target populations, specifically for which donated drugs are currently available from the global drug donation programmes through the World Health Organization (WHO).

In recent years, the STH and SCH communities have each launched a disease-specific structure, the Global Schistosomiasis Alliance (GSA) and STH Coalition, respectively, intending to bring together a wide range of stakeholders interested in controlling or eliminating each disease as a public health problem. These structures have increased focus on both SCH and STH, however because of the natural linkage between the two diseases, the STH-SCH Coordination Group continues to be an important mechanism and platform for formally linking the two among the NGDO members.

### 2. The purpose of this group

- 2.1. To promote strategic partnerships, coordination, and coordinated advocacy to ensure continued comprehensive control/elimination of STH and SCH in accordance with WHA Resolutions 54.19 and 65.21 and WHO technical guidelines
- 2.2. To foster Monitoring & Evaluation (M&E) of SCH and STH control/elimination activities through an integrated framework that is aligned with the WHO technical guidelines, to evaluate progress toward elimination as a public health problem and interruption of transmission.
- 2.3. To advocate for resources to scale up and sustain the necessary treatment coverage in different at-risk groups
- 2.4. To promote the BEST (Behaviour, Environment, Social Inclusion and Equity and Treatment and Care) Framework for comprehensive control/elimination of SCH and STH
- 2.5. To serve as a forum for communication and collaboration on best practises and lessons learnt among the NGDO members engaged with SCH and STH control programs
- 2.6. To promote interest in supporting SCH and STH control/elimination activities among any interested parties not currently SCH/STH group members
- 2.7. To identify and promote opportunities to engage in operational research on SCH and STH control/ elimination



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- 2.8. To be the voice for the SCH and STH Group members at international forums to ensure that their interests and concerns are represented

### 3. Membership

Membership in the SCH-STH Coordination Group is open to all NGOs that are directly or indirectly involved in supporting SCH and STH control/elimination programs in endemic countries. Non-NGOs (donors, UN agencies, government organizations, universities, and research institutions) are considered as non-voting **associate members** if they wish to join the group.

Any organization wishing to join the Group should contact the Chair and Vice Chair of the Group with their intention to join, their organizational background and their activities in supporting SCH and STH control/elimination. The Steering Group (defined below) will determine the status of the organization as a member or an associate member and seek approval via emails from the Group members and final confirmation at the annual meeting.

The Group members shall commit to adhering to the NNN Framework of Engagement and the TOR of the SCH and STH group and to participating in group discussions and annual meetings.

### 4. Governing Structure

The Group is intentionally established with a light governing structure so as to focus on collaboration and communication and to maintain flexibility to respond to the needs as identified by the Group members.

- 4.1. The group will have three positions, a Chair, a Vice Chair and an immediate past Chair, to form the Steering Group. Each position is held by an individual from a member NGO, rather than his/her organization, therefore it is not transferable within the same organization.
- 4.2. Each position will have a *one-year term*. At the end of the one-year term the Chair will become the immediate past Chair. The Vice Chair will take over to become the new Chair. A new Vice Chair will be elected by the voting members of the Group (one vote per member NGO).
- 4.3. The Chair will
  - 4.3.1. Be primarily responsible for communicating regular group updates and guiding discussion amongst members
  - 4.3.2. Represent the SCH-STH Coordination Group on the Executive Committee (ExCo) of the NNN and regularly attend the ExCo meetings
  - 4.3.3. Be the lead liaison of the Group with WHO/ESPEN, STH Coalition, GSA plus other key groups, disease specific organizations and United Nation groups on communication and coordination on SCH and STH related activities and priorities
  - 4.3.4. Be responsible for leading development of the agenda for the annual meeting
  - 4.3.5. Coordinate the follow-up activities on any action points or recommendations from the Group's annual meeting
  - 4.3.6. Ensure safe keeping and archiving of the Group documents and meeting reports



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### 4.4. The Vice Chair will

- 4.4.1. Assist the Chair in fulfilling the above duties
- 4.4.2. Represent the SCH-STH Coordination Group on the ExCo of the NNN and other relevant meetings when the Chair delegates
- 4.4.3. Deputize the Chair in communicating to the Group members

### 4.5. The immediate past Chair will

- 4.5.1. Be a member of the Steering Group to advise and preserve institutional memory.
- 4.5.2. Ensure safe handover of the Group archive to the new Chair
- 4.5.3. Represent the Chair at meetings if the Vice Chair is absent

## 5. Communications and Touchpoints

The group's primary mode of regular communication will be via emails to which all members and associate members can contribute and learn from. Each member or associate member organization of the group shall appoint one or two primary points of contact (one for SCH and one for STH) to serve as the key communication representatives of their NGDO. The points of contact will be the persons to whom the communications on Group administrative matters will be addressed while a wider list of communication will be used for information sharing, etc. Face-to-face meetings will be held annually as part of the NNN Annual Meeting, with an agenda developed in advance by the Chair and Vice-Chair in consultation with group members. Additional meetings may be called if the group deems them important for the goal of increased collaboration and communication.