

# The Neglected Tropical Disease Non-governmental Development Organization Network (NNN): the value and future of a global network aiming to control and eliminate NTDs

Lisa A. Rotondo<sup>a,\*</sup>, Wendy Harrison<sup>b</sup>, Simon Bush<sup>c</sup>, Adrian D. Hopkins<sup>d</sup> and Kim Koporc<sup>e</sup>

<sup>a</sup>NTD NGDO Network, RTI International, Washington, D.C., USA; <sup>b</sup>NTD NGDO Network, Schistosomiasis Control Initiative, Imperial College, London, UK; <sup>c</sup>NTD NGDO Network, Sightsavers, Haywards Heath, West Sussex, UK; <sup>d</sup>NTD NGDO Network, Mectizan Donation Programme, Task Force for Global Health, Decatur, GA, USA; <sup>e</sup>NTD NGDO Network, Children Without Worms, Task Force for Global Health, Decatur, GA, USA

\*Corresponding author: Tel: +1 202 974 7890; E-mail: lrotondo@rti.org

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## The NNN and its origins

The Neglected Tropical Disease Non-governmental Development Organization Network (NNN) ([www.ntdngdonetwork.org](http://www.ntdngdonetwork.org)) is a global forum for non-governmental development organizations (NGDOs) working to control or eliminate neglected tropical diseases (NTDs): currently including, leprosy, lymphatic filariasis (LF), onchocerciasis, schistosomiasis (SCH), soil-transmitted helminthiasis (STH) and trachoma. Each of these diseases has elimination as a target where feasible and each receives generous donations of medicines from the pharmaceutical industry. The NNN was formed at a meeting in Accra, Ghana, in September 2009 when several existing NTD-specific coordination groups combined forces following a general trend towards integrated NTD control and elimination. Today, the NNN is composed of five NTD-specific NGDO coordination groups: the LF NGDO Network; the International Coalition for Trachoma Control (ICTC) (<http://www.trachomacoalition.org/node/873>); the NGDO Coordination Group for Onchocerciasis Elimination; the SCH/STH NGDO Coordination Group; and the International Federation of Anti-Leprosy Associations (ILEP) (<http://www.ilepfederation.org/about-us/history-of-ilep/>). In addition to these five disease-coordination groups, the NNN has two thematic working groups: 1. Water, Sanitation, and Hygiene (WASH), and 2. Disease Management, Disability and Inclusion (DMDI). These working groups allow NNN members to address key cross-cutting issues that are common to the targeted NTDs.

Together, these coordinating and working groups (Figure 1 and Table 1) comprise nearly 80 NGDO members of the NNN, working directly to support the world's most underserved populations suffering from the NTDs<sup>1,2</sup> by:

1. being strategic innovators in facilitating the delivery of medicines against NTDs through partnerships with ministries of health, pharmaceutical donors, drug donation programs,

community drug distributors and the beneficiary communities themselves;

2. providing logistical and technical support in endemic countries for the transportation, storage and distribution of NTD medicines and commodities;
3. providing training before and supervision during mass drug administrations (MDAs);
4. supporting the monitoring and reporting of serious adverse events;
5. promoting innovation in data collection and reporting following MDAs;
6. advocating for, and providing technical assistance for, the development of standardized ordering and reporting on use of NTD medicines to donors and international bodies; and
7. contributing support for global NTD monitoring and evaluation platforms, disease-specific strategic planning and costing, tool development, operations research, and technical assistance and guidelines development.

## The NNN's goal and objectives

The NNN's overall goal is to contribute to the global prevention, control and elimination of NTDs outlined within the internationally agreed WHO NTD Roadmap.<sup>3</sup> A key relationship for NGDOs in the NNN is with disease-endemic country governments, working in direct support of the WHO NTD Roadmap and World Health Assembly resolutions. The NNN promotes comprehensive approaches that prevent, treat and manage consequences of the targeted diseases of poverty. As an innovative platform for shared learning and programming, the NNN supports the generation and dissemination of evidence-based practices.

Its objectives are to:

1. expand and increase the effectiveness of NTD advocacy by giving NGOs a unified voice at international, regional and national forums;
2. facilitate the formation of partnerships among NNN members at international, regional and national levels;
3. coordinate NGO activities (to avoid duplication of efforts), identify opportunities for synergy, track progress towards goals, and identify operational and other research needs;
4. share technical updates, develop and support preferred practices, and use all channels available to advocate for and facilitate the development of WHO guidelines to achieve our common goals;
5. engage non-health sectors that are required for the long-term sustainable control and elimination of NTDs;
6. present the common interests of implementing NGOs with a unified voice for the mobilization of resources.

Crucial to the success of the NNN and its meetings are the observer-participant colleagues from WHO, donor organizations, pharmaceutical companies, foundations and endemic country governments (typically Ministries of Health but increasingly from other sectors as well). These groups are active participants and support the NNN's efforts at enhanced coordination to achieve the collective global NTD goals.

## NNN impact

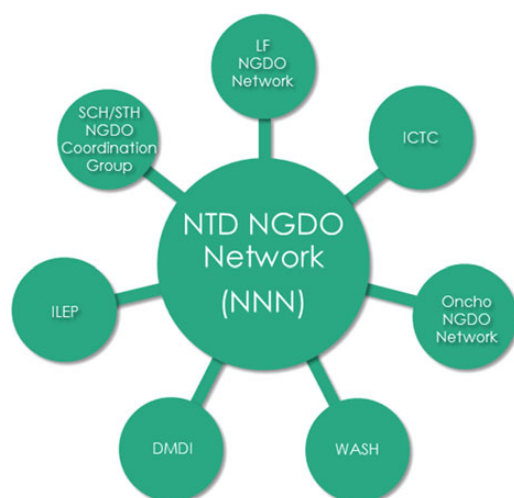
The accomplishments of the NNN demonstrate the comparative advantage of NGOs—particularly when united—in supporting endemic countries to tackle NTDs.<sup>4,5</sup> Its successes should be understood in the context of the NNN's broader role within the

global NTD community as a facilitator of collaboration with numerous stakeholders. The NNN's impact is the result of joint efforts in support of host country governments and the WHO NTD Roadmap.

Importantly, NGOs focus on ensuring that NTD programming is built upon and integrated into national health systems, strengthening these at multiple levels and pursuing comprehensive development approaches to advance NTD elimination. As a large global network, the NNN advocates at country, regional and global levels for addressing NTD-related morbidity and disability and for promoting an inclusive development agenda. In addition, its advocacy for water, sanitation and hygiene have kept these issues at the forefront of NTD community discussions with WHO and other partners, indeed culminating in the launch of the 2015 WHO report on 'Water, Sanitation, & Hygiene for accelerating and sustaining progress on Neglected Tropical Diseases: a Global Strategy 2015–2020'.<sup>6</sup> In concert with this strategy, the NNN's WASH Working Group is currently facilitating the identification of a core set of indicators to promote collaboration between the WASH and NTD communities. At the 2015 NNN meeting, the WHO NTD department publicly acknowledged the important role the NNN played in keeping WASH and disease management on its NTD agenda.

The NNN has increased the expansion and effectiveness of NTD advocacy by giving NGOs a unified voice. Indeed, the NNN has recently assumed key positions in global partnership and advisory bodies, particularly through providing expertise for the annual reporting on the progress towards the 2012 London Declaration targets.<sup>7</sup> The NNN will also represent the NGOs on the transitional steering committee of WHO AFRO's new Expanded Special Project for Elimination of NTDs (ESPEN).

Influencing policy for sustainable NTD control and elimination has been another important challenge for the NNN. Although the importance of the NTDs could be appreciated in several of the previous Millennium Development Goals (MDGs) defined in 2001 by the United Nations—namely, MDG 1 'Eradicate extreme poverty and hunger', MDG 6 'Combat HIV/AIDS, malaria, and other diseases,' and MDG 8 'Develop a global partnership for development'—they were not identified specifically. Strong advocacy was required for their inclusion in the United Nation's post-2015 goal setting. Working with other advocacy partners, the NNN advocated successfully for the inclusion of NTDs in the Sustainable Development Goals (SDGs), so that going forward NTDs will be explicitly addressed through SDG Goal 3 'Good health and well-being'/Target 3.3 'By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, waterborne diseases and other communicable diseases.' Most importantly, a specific indicator for all NTDs as advocated for in the NNN's 2015 Abu Dhabi Declaration,<sup>8</sup> has been provisionally approved for inclusion, ensuring that progress towards this important global goal must be measured.



**Figure 1.** The structure of the Neglected Tropical Disease Non-governmental Development Organization Network (NNN) in 2015. DMDI: Disease Management, Disability and Inclusion; ICTC: International Coalition for Trachoma Control; ILEP: International Federation of Anti-Leprosy Associations; LF: lymphatic filariasis; NGDO: non-governmental development organization; SCH: schistosomiasis; STH: soil-transmitted helminthiasis; WASH: Water, Sanitation and Hygiene. This figure is available in black and white in print and in colour at International Health online.

## Future direction of the NNN

The NNN was designed to be a loosely organized umbrella network to enhance NGO coordination and minimize duplication of effort. Its strengths have been both in improving coordination and collaboration and in helping track progress towards global

**Table 1.** Neglected tropical disease (NTD) Non-governmental Development Organization (NGDO) groups within the NNN and their associated Global Alliances

Disease-specific NGDO coordination groups in the NNN	Year established	Global Alliance supported
Lymphatic Filariasis NGDO Network	2004	Global Alliance for the Elimination of Lymphatic Filariasis (GAELF)
International Coalition for Trachoma Control (ICTC)	2004	Global Alliance for the Elimination of blinding Trachoma by the year 2020 (GET2020)
Schistosomiasis/soil-transmitted helminthiasis NGDO Coordination Group	2014	Global Schistosomiasis Alliance (GSA)
Onchocerciasis NGDO Coordination Group	1992	STH Coalition
		African Programme for Onchocerciasis Control (APOC; through 2015)
		Onchocerciasis Elimination Program of the Americas (OEPA)
Federation of Anti-International Leprosy Associations (ILEP)	1975	None currently

goals. The NNN aims to share expertise and local knowledge to maximize impact, to identify and fill gaps in funding or other resources (e.g., medicines, diagnostics) and to collect data to support unified advocacy messaging.

As a flexible network, the NNN must remain dynamic in order to respond to changing programmatic, technical and funding landscapes, and to accommodate new groups and partnerships. Challenging issues on the horizon include the role of vector control for the NTDs, gender equality and identification of new operational research needs to achieve the global targets. Therefore, the NNN must continue to expand its cross-disciplinary reach, further enhancing the impact of preventive chemotherapy and intensified disease management. In addition, the increased focus of WHO on a number of the zoonotic NTDs and their impact on human health and livelihoods means that the NNN might need to engage with the veterinary public health sector and accommodate additional groups to address the human-animal interface as they are established.

Advocacy and facilitation of additional partnerships will continue to be uniquely important for the NNN in the global NTD community. NNN members have already facilitated the formation of partnerships with national NTD coalitions, such as the UK Coalition Against NTDs and the German NTD Coalition. In coming years, momentum towards NTD goals will grow and additional funders, implementing collaborators, and technical and research partners must be engaged. The NNN will continue to promote the establishment of regional networks and national level NGDO coalitions and will seek to increase the number and diversity of stakeholders committed to global NTD control and elimination, particularly engaging those outside the health sector.

Perhaps most importantly, as in-country implementers and partners to national programs, the NNN members must continue to carry forward the voices of the endemic communities with whom the NGDOs work so closely. As national programs move towards their NTD control and elimination goals, the role of the NNN will become even more crucial to ensure that evidence-based technical support is available in developing strategies for the final programmatic stages. The NNN will continue to raise awareness among international policy makers and the global development community that NTDs are a key barrier to the attainment of the SDGs and poverty alleviation and that there is an

urgent need to support these public health interventions in communities of extreme poverty.

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