

Prevention and treatment of neglected tropical diseases: past, present and future

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In September 2015, over 220 individuals representing non-governmental development organizations (NGDOs), donors, ministries of health, WHO and UNICEF convened in Abu Dhabi for the 6th Annual Meeting of the Neglected Tropical Disease (NTD) NGDO Network (NNN6), hosted and sponsored by Christian Blind Mission, with additional support from Sightsavers and Emirates. The meeting provided an opportunity to reflect on accomplishments in the prevention, treatment and management of consequences of NTDs, which affect the poorest of the poor. This special supplement includes articles on cross-cutting issues affecting the control and elimination of NTDs, achievements spearheaded by NNN member organizations and priorities for future work. These articles expand on presentations given at NNN6.

The introductory article (p.i4), by the current and past chairs, describes the NNN's structure, accomplishments and future directions.¹ For an example of how NNN's community works together, the article by Kebede and colleagues (p.i34) presents a case study of how NGDOs and the Ministry of Health, with resources from donors, combined forces to scale-up NTD interventions to treat at-risk populations across the entire nation of Ethiopia.² Beginning in 2016, NGDOs will have a larger role in the coordination of NTD activities in the African region with the establishment of a new WHO coordinating entity. The article by Hopkins (p.i28) describes the role and structure of this new entity, called the Expanded Special Project for the Elimination of NTDs (ESPEN), which includes representation of the NNN.³

The theme of NNN6 was 'NTDs: post Millennium Development Goals and pre Sustainable Development Goals (SDGs)' to advocate for a proposed NTD global indicator for measuring progress towards SDG 3: the number of people requiring interventions against NTDs. Members signed the Abu Dhabi Declaration, affirming their commitment to 'support data collection for the NTD global indicator,' 'support ministries of health to analyze and publish the results of the data collected' and 'work in partnership

with key stakeholders and decision makers, nationally and internationally, to achieve control and elimination targets through prioritization of NTDs.'⁴ The paper by Fitzpatrick and colleagues (p.i15) presents the case for the NTD global indicator.⁵

As the NTD programs continue to scale-up, questions arise regarding the most effective approaches and, as the WHO NTD Roadmap⁶ target dates for elimination of NTDs loom closer, new tools are needed to speed up the process. The article by Toledo and colleagues (p.i12) presents a framework for a rapid research response to challenges faced by NNN member organization initiatives.⁷

At NNN6, we celebrated success in bringing to the forefront cross-cutting issues: the need for water, sanitation and hygiene (WASH) to prevent infection; and the need for management of consequences from NTDs. For example, WHO's global strategy to mobilize WASH resources to sustain gains made in the control and elimination of NTDs was launched⁸ and a new toolkit for cross-NTDs morbidity and disability assessment was introduced.

A summary of WHO's global strategy is presented in a paper by Velleman and colleagues (p.i19),⁹ along with a complementary paper by Waite and colleagues (p.i22),¹⁰ which presents the recent history of collaboration and identifies priorities and mechanisms for enhanced coordination between the NTD and WASH communities. This supplement also includes three articles on stigma and other consequences from NTDs. The first article, by Mieras and colleagues (p.i7), presents the outcomes of a workshop convened by the Morbidity Management and Disability Working Group of the NNN.¹¹ The second article, by Hofstraat and van Brakel (p.i71),¹² presents the results of a literature review to identify the extent of social stigma related to NTDs, and the third article, by van 't Noordende and colleagues (p.i53), documents the process undertaken to develop the toolkit for cross-NTD morbidity and disability assessment.¹³

The NNN6 also provided an opportunity for individuals to share their stories of working with NTDs. The END Fund sponsored a 'Listening Tour' to give meeting participants an opportunity to share their stories (<https://soundcloud.com/the-end-fund/sets/listening-tour>). My (Kim Koporc's) story started 25 years ago, as a Peace Corps Volunteer in Ghana. I was responsible for promoting WASH in 35 rural communities that made up the district of Adansi West. In those communities, I saw people with leopard skin—a symptom of onchocerciasis. At the time, I had no idea what caused it. I saw blind people begging for money—people probably blind due to trachoma. I saw my first leprosy patient who, in addition to his sickness, was a victim of severe social stigma. The disease left him with no nose and no mouth, and society put him on a leash attached to a collar around his neck. I saw children with schistosomiasis and soil-transmitted helminthiasis. I knew what caused those diseases, but treatment was not readily available in clinics and certainly not in the communities. WASH interventions were my only weapons.

My (Paul Emerson's) story with NTDs started in the 1980s when, fresh out of my own high schooling, I became a volunteer teacher in rural Kenya. There, mothers and fathers accepted malaria, intestinal worms and dysentery as facts of life and that, apart from prayer, they were powerless to do anything about them. I avoided malaria with prophylaxis, but felt the insidious loss of energy and weakness associated with my own infections with amoeba, hookworm and trichuris. Although I had a safety net, I also experienced helplessness when I saw how much of my meagre salary was to be spent on medication and with it the realization that I could be bankrupted by a diagnosis. But how much worse would that be if I had no safety net? What if the decision really was to buy food for my family or medication for one sick family member? I was struck that so much of the course of our lives is determined by where we were born and the inequality made me angry. Why should industrious, hard-working and loving people have so much stacked against them? Why should the Kenyan pupils have to contend with the debilitating effects of worms and intestinal protozoa in addition to studying in a foreign language (and with teachers barely old enough to shave)? How were people to be expected to get out of the grip of cycling ill health and poverty when worms and protozoa kept them there? I resolved that I would do what I could to educate individuals and communities to protect themselves and their families from infectious disease, and to provide access to the drugs and simple technologies that would enable them.

Fast forward 25 years and look at all that has been accomplished! Ministries of health have received and distributed en masse unprecedented quantities of donated medicines. The NTD and WASH communities are more closely linked than ever before, thanks particularly to the recent WHO NTDs and WASH Strategy. The NNN has brought to the forefront the importance of comprehensive interventions for NTDs, including prioritizing morbidity management and reduction of stigma and discrimination. We can now envisage a world where these horrible diseases are no longer a fact of life just because of where you are born.

What can we accomplish in the next 5, 10 or 20 years as we work towards the targets set out in the WHO NTD Roadmap and the SDGs? What can we contribute? By joining forces, the coalitions representing onchocerciasis, trachoma, schistosomiasis, soil-transmitted helminthiasis, lymphatic filariasis and leprosy have been able to demonstrate success, and the clear substantial progress has attracted more donated drugs, more money and more

attention. Several of the NTDs are rather less neglected than they once were. To those academics, donors and NGOs who focus on Chagas disease, cystercercosis and Echinococcus, treponematoses, Buruli ulcer, the leishmaniasis, foodborne trematodiasis, podocniosis and other NTDs, we say 'join together' and participate in the NNN for together we have a louder voice and together we can achieve more for those at risk and suffering from these preventable diseases. Collaboration, monitoring and evaluation, research and development, and cross-sectoral collaboration will continue to be important—all principles and approaches reaffirmed by NNN members in the Abu Dhabi Declaration.

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