

**Executive Summary of Conclusions and Proceedings of the 4th
Meeting of the Neglected Tropical Disease NGDO Network
(NNN)
Brighton, UK,
18-20 September 2013**

1 Key conclusions from the meeting:

- 1.1 There is great concern that, although largely adequate drugs have been committed by the Pharmaceutical industry for blinding trachoma, lymphatic filariasis (LF), onchocerciasis, schistosomiasis (SCH), and soil-transmitted helminthiasis (STH), the absorptive capacity in many countries is insufficient. Scale up to reach the WHO-proposed trajectory is not feasible based on current funding for implementation. NNN noted the urgent need to address the mobilization of resources needed to close the implementation gap in order to meet London Declaration's 2020 goals. It was recommended that members should work together and individually to attract new funding from international and national donors, including donors in the endemic countries.
- 1.2 Members should make every effort to closely collaborate in their NTD program(s) implementation and advocate with donors, policy makers, and program implementers at all levels for:
 - 1.2.1 Continuum of care (COC: prevent – treat – rehabilitate – integrate) beyond mass drug administration (MDA) to include morbidity management and disability prevention (MMDP), stigma reduction, support for mental health care and livelihood. The NNN agreed to set up a COC working group with representation from the various disease specific groups to work closely with WHO (global, regional and country levels) and other stakeholders to coordinate advocacy efforts and develop COC tools;
 - 1.2.2 Comprehensive and inter-sectorial approaches to control and eliminate NTDs, including water, sanitation and hygiene education (WASH) and vector-control interventions, including insecticide-treated bed-nets (ITNs) distribution, and integrated care.
 - 1.2.3 Effective coordination / integration of interventions for comprehensive and efficient NTD programs.
- 1.3 Participation in the NNN meeting has been growing with each meeting, involving a new range of stakeholders, and attracting an expanding membership base.

2 Detailed Review of Proceedings:

2.1 NNN – Simon Bush (Sightsavers), Chair – The NNN:

- 2.1.1 Welcomed the leprosy community as a member of the NNN.
- 2.1.2 Launched the new NNN website: www.ntdngdonetwork.org. Please send comments/suggestions to Joni Lawrence at jlawrence@taskforce.org.
- 2.1.3 Acknowledged the formal launch of the new NTD mapping tool: www.ntdmap.org for schistosomiasis, STH, and trachoma.
- 2.1.4 Should encourage NGOs to provide the donor community and governments with an estimate of the costs to reach elimination targets. Some work is being done on this, but more is needed. The donor community would find it useful for NGOs to estimate unit costs for implementation taking into consideration the context for all scenarios i.e. location (urban, rural), the different components for NTD control and elimination (MDA, morbidity management, surgery, provision of water and sanitation facilities, environmental behavior). There needs to be a mechanism to identify actual costs to facilitate planning.
- 2.1.5 Should provide donors with success stories to enhance advocacy for additional funding.
- 2.1.6 Should advocate to ensure that NTDs remain on the post-2015 WHO agenda.
- 2.1.7 Should include a session on elimination and what it means for each disease group on the agenda for the next meeting.

2.2 Simon Bush handed the chair over to Kim Koporc (Children Without Worms). The new vice-chair is Lisa Rotondo (RTI Envision project).

2.3 WASH Session –Stephanie Ogden (CARE USA/Children Without Worms), Moderator –

- 2.3.1 Opportunities to support WASH and the greater preventive environment for NTD control:
 - When communicating, members should frame NTDs within larger paradigms/sector perspectives to reflect how we relate to issues like environmental enteropathy and to other stakeholders and sectors.
 - Joint advocacy is needed for WASH and NTD control, including for greater investment in WASH and in preventive initiatives.

- Members should find ways to involve the private sector more fully by further investigating how the private sector can add value to WASH and NTD control and sharing case studies of effective partnerships.
- There was recognition by the members of the direct correlation between the effectiveness of NTD projects and WASH projects, as the achievement of project goals and objectives are intrinsically linked.
- Measurable joint indicators for WASH and NTDs are needed for joint accountability and to better understand long term impact. Diseases like enteropathy affect development – not just health.
- Community-based approaches to leprosy and disability have proved effective, therefore a shift to rights-based indicators (applicable to WASH) recommended over disease-based indicators (traditionally for NTDs)
- NTD Department of WHO will engage key stakeholders including UNICEF and World Bank.
- Clear strategies for disease control that outline the role of WASH need to be defined.
 - WASH plays a key role in the reduction of disability (e.g. clean water is crucial in the caring and treatment of leprosy)
 - A clear WASH strategy is needed for the inclusion of people with disabilities (PWDs) within community based solutions
- Members should investigate ways to and share best practices about effectively mobilizing communities affected by disease.
- WASH and NTD organizations should link with existing national and international coalitions to increase the impact of their work.
- Harmonized and comprehensive messaging is needed, i.e. complete hygiene for multiple health gains.
- Evidence based advocacy is needed for WASH.
- The WASH organizations should take advantage of the ‘supply chains’ and training mechanisms of the NTD sector to engage in wide-scale hygiene messaging.

2.4 WHO Update – Dirk Engels (WHO, Department of NTDs)

- 2.4.1 The WHO Partnership questionnaire should be routed through the NNN as a practical way of working out which NGOs are where and what they are supporting.
- 2.4.2 The NNN encourages WHO to develop a comprehensive manual on chronic MMDP for NTDs and encourages members to collaborate and support this effort through technical consultation.

2.5 Updates from NNN Member Disease Groups

2.5.1 **International Coalition for Trachoma Control (ICTC) –**

Chair - Martin Kollmann (CBM)

Vice Chair – Virginia Sarah (Fred Hollows Foundation)

Past Chair – Paul Emerson (The Carter Center)

- ICTC is a community of practice in support of GET 2020 and the SAFE strategy. Building on an active and diverse membership with a strong sense of togetherness ICTC has increasingly been able to attract resources and to facilitate the implementation of SAFE through advocacy and technical support. The trachoma community is now challenged by unprecedented opportunities to end this ancient disease.
- The Global Trachoma Mapping Project (GTMP) and the Global Atlas of Trachoma (GAT) have led to an unprecedented increase in our knowledge and understanding of where best to focus our resources and to plan and coordinate effective trachoma elimination activities.
- Among its strategic priorities, the coalition develops and disseminates resource material in the form of preferred practice manuals available online and in print in several languages (www.trachomacoalition.org) (e.g. in 2012, ICTC held a Global Scientific Meeting on Trachomatous Trichiasis (TT), which led to the development of a report on “preferred practices” for surgical management of TT, surgical quality, and ways to improve surgical uptake and output for TT.
- ICTC has also collaborated closely with WHO in developing the 2nd edition of the Trichiasis Surgery for Trachoma book (training and certification of TT surgeons manual). This was available in draft format at the NNN.
- In 2012, ICTC documented MDA preferred practices for trachoma elimination, which led to the development of an ICTC manual on preferred practices for MDA delivery for trachoma.
- ICTC is also in the process of preparing similar resource material for the F & E components of SAFE (linked to water, sanitation and health promotion).

- ICTC collaborated closely with IAPB in developing an *Essential List for Trichiasis Surgery* for the IAPB standard list (now available online).
- ICTC actively engages with the WASH sector, both through membership and inter-sectorial advocacy activities (e.g. round tables, data collection, and publications).
- ICTC has developed unit costs for global advocacy and indicator based milestones. The coalition collaborates systematically with the BMGF and WHO on the harmonization of monitoring progress in the context of GET 2020 and the London Declaration 2012.
- More than \$150 million has been leveraged for trachoma control and elimination of blinding trachoma through ICTC in the last 12-18 months.

2.5.2 **ILEP (The International Federation of Anti-Leprosy Associations) –**

Doug Souter, General Secretary (ILEP)

Andrew Clark, Assistant General Secretary (ILEP)

- There is potential for collaborative approaches for NGOs to work together on:
 - Disease control
 - Morbidity management and prevention of disability
 - Community-based rehabilitation (CBR)
 - Stigma reduction
 - Advocacy for persons affected
 - Accessing funding
- Intensive disease management (IDM) cannot be time limited by a 2020 target; unless we can scale up resources for R&D of new tools to break transmission, leprosy and its disabling consequences will require IDM well beyond 2020.
- Intensive, innovative and collaborative disease management will be needed if we are to avoid ‘neglected’ diseases becoming ‘re-emerging’ diseases.

2.5.3 **NGDO Coordination Group for Onchocerciasis Elimination –**

Chair – Frank Richards (The Carter Center)

Vice Chair – Daniel Shungu (United Front Against River Blindness)

Past Chair – Franca Olamiju (MITOSATH)

- The experience of the Onchocerciasis NGDO group has been well documented in the peer reviewed literature. Best practice experiences should include publishing NGDO work in peer reviewed journals so as to improve overall advocacy for NTD control/elimination, as well as to have maximum influence on national policy and WHO global guidelines.
- In solidarity with the general trend in the African onchocerciasis community, the Group will focus on “Getting to Zero” transmission of onchocerciasis in all endemic areas. This is distinguished from ‘Elimination as a Public Health Problem’ which is a term used for high level control but not transmission interruption. Accordingly, at its 41st meeting earlier in 2013, the group changed its name from NGDO Coordination Group for Onchocerciasis **Control** to the NGDO Coordination Group for Onchocerciasis **Elimination** to make the distinction in the new paradigm
- The group will enhance efforts to communicate the new vision of elimination.
- In order to enrich the onchocerciasis advocacy messages with respect to the London Declaration, the Group strongly recommends that African onchocerciasis **elimination** milestones are more clearly articulated in alignment with the year 2020 NTD goals. Currently the key onchocerciasis milestone is the elimination of onchocerciasis from the Americas by 2015. Elimination milestones for Africa and Yemen are not well articulated.
- The Group is providing detailed input into the new APOC Concept Note which outlines the vision for onchocerciasis and lymphatic filariasis in Africa post-2015. This initiative is driven by the epidemiological overlap of the two conditions, the fact that both use ivermectin, both are transmission elimination programs, and both must stop MDA in a coordinated manner in order to conduct mandatory post MDA surveillance. Adding lymphatic filariasis into APOC activities will require a major change to the APOC mandate. The Oncho Group has reached out to the NGDO Network for LF related to the new APOC mission, and asked the Network to consider reviewing the draft APOC Concept note from the perspective of the LF agenda and needs, and the approach to an enhanced operational partnership with joint onchocerciasis/LF activities in Africa.

2.5.4 **STH and Schistosomiasis NGDO Coordination Group**

Chair – Kim Koporc (Children Without Worms)

- The STH/SCH NGDO Coordination Group is a diverse group with a shared vision of elimination of STH and Schistosomiasis. We are a forum for sharing information and advocacy to promote comprehensive, evidence-base strategies.

- Vitamin Angels announced their commitment to scale-up albendazole distribution to all eligible children already receiving vitamin A from Vitamin Angels starting in FY 2014
- Prevention activities, including provision of water and sanitation and hygiene education should feature more prominently in the global strategy to control STH.
- With the new goal of elimination, the SCH NGDO community needs new diagnostic tools, revised indicators, tools for measuring indicators, and clarification definitions.

2.5.6 NGDO Network for Lymphatic Filariasis –

Chair – Ann Varghese (IMA World Health)

Vice Chair – Emily Heck Toubali (Helen Keller International)

Past Chair – Pierre Brantus (Handicap International)

- Pierre Brantus handed over the chair to Ann Varghese. Emily Toubali of HKI was elected as the new vice-chair.
- Endemic countries should implement the recommended minimal activity package (hygiene, elevation, exercises, footwear).
- Depending on the situation more complex morbidity management tools (physiotherapy, compression, ayurvedic medicine) may be applied.
- It is important to note that MMPD may also improve therapeutic coverage of MDA as demonstrated in several studies.
- An updated public health and programmatic approach is now available through the WHO MMDP manual for national LF program managers.
- The LF Network will work closely with the Oncho NGDO group, APOC, and other stakeholders to collaboratively address LF/Oncho overlap issues
- Issues under discussion:
 - aspects of the pathogenesis of acute attacks and potential treatment implications,
 - adaptation of bandaging material to a tropical environment,
 - psychosocial support,
 - how best to implement basic care at the country level to achieve the elimination goal by 2020,

- NGOs must play a major role in supporting national programs: availability for technical support to MoH to enable implementation of activities in at least one district,
- Disease specific LF-lymphoedema management, through the community approach and within the primary health care system, is currently identified as a priority by the global program.
- Integrated LF-lymphoedema management:
 - With other lymphoedema and/or causing conditions. Managing the condition independently of its cause/disease (e.g. LF, leprosy, Buruli ulcer, diabetes and other leg problem) by applying the WHO recommended minimal package.
 - With chronic wound care. This involves the integrated implementation and development of integrated dressing material and treatment protocols for different levels of management.
 - There are several opportunities for integrated approaches for the management of lymphoedema. Irrespective of the preferred approach, the priority for NGOs remains to support national programs in the successful implementation of MMDP so that all endemic countries have implemented effective MMDP programs by 2020.
 - Related to MDA, the LF NGO group agreed to review the draft APOC Concept note, which is proposing an enhanced operational partnership with joint onchocerciasis/LF activities in Africa.
- Following an earlier questionnaire to the GAELF Representative Contact Group (RCG) a meeting of the GAELF Executive Group and RCG will be convened in Washington DC prior to the ASTMH to consider and agree a new management structure for GAELF;
- Venues for GAELF8 in 2014 are being considered preferably in Africa and aligned to other meetings. Potential opportunities for alignment are with APOC JAF, a follow-on London Declaration meeting or an Atlanta NTD Center meeting;
- Partners at the meeting provided an update of country implementation progress towards elimination.

2.6 Continuum of Care (COC) session –Martin Kollmann (CBM), Moderator

- 2.6.1 There are many opportunities for integrated approaches in MMDP (integrated care approaches from LF, leprosy, diabetes). Systematic, evidence-based and innovative

approaches are needed to overcome critical issues and improve the quality of care delivery (examples from trachoma and LF).

- 2.6.2 NGOs can play a critical role in advocating for the successful integration of MMDP into comprehensive NTD programs.
- 2.6.3 Based on a continuum of care approach, community based strategies (e.g. CBR) can be effective for the inclusion of persons with NTD-related disabilities in society and in mainstream development.
- 2.6.4 Addressing stigma management and the mental health impact of NTDs are essential components of comprehensive NTD programs.
- 2.6.5 NTD programs should be human rights-based. This includes the right of persons affected by these conditions to be involved in all stages of program planning and management.

2.7 Case study on Nigeria –Adrian Hopkins (Mectizan Donation Program), Moderator

- 2.7.1 Nigeria has a tremendous NTD burden, being number 1 for onchocerciasis and schistosomiasis in the world, and number 3 (after India and Indonesia). Nigeria has had success against NTDs, including eradication of Guinea worm disease, sustaining the largest ivermectin distribution program in the world, and providing multiple examples of partnership for NTD elimination/control, and extensive contribution to global knowledge (including peer reviewed publications). Ministry of Health leadership, structures for constructive collaboration of NGOs and donors, and strong human resources were noted.
- 2.7.2 No single organization can control NTDs in a country on their own. The MOH must be in the lead but with full participation of all stakeholders, including NGOs, to achieve implementation goals.
- 2.7.3 NTD programs should build on existing projects already implementing MDA to avoid “reinventing the wheel.”
- 2.7.4 NGOs should undertake operational research with ministries of health to resolve issues and develop their programs allowing expansion and improving performance.
- 2.7.5 The linkage between NTD and malaria programs was noted, in consideration of synergies related to similar anopheline vectors (LLIN and MDA control) and anemia concerns (STH/Schisto and malaria). It was recommended during the meeting that NNN should consider inviting the malaria community to its next meeting to overlapping interests.

3 Next Meeting –

- 3.1 Paris, France – the week of September 22, 2014