

**NNN LF NGDO NETWORK MEETING  
WEDNESDAY, 26<sup>TH</sup> SEPTEMBER 2018  
UNECA, ADDIS ABABA, ETHIOPIA**

<b>ORGANISATION/ DESIGNATION</b>	<b>ATTENDEES</b>
AIM	Patrick Atkpo
American Leprosy Missions	Linda Lehman
Bangladesh MoHFW	Mohammad Jahirul Karim
BMGF	Molly Mort
Carter Center (Ethiopia)	Yewondwassen Bitew, Avagaw Lameash, Aderajau Mohammed
CBM	Emeka Nwefoh, Lebon Safari, Johan Willems
Consultant	Adrian Hopkins
END Fund	Claire Chaumont, Carlie Congdon
Footwork	Gail Davey
GAELF/LSTM NTDs	Joan Fahy
GLRA, Ethiopia	Solomon Sisay
HANDS	Elisha Agagak
HKI	Zeina Sifri
Indian NTD Network Desta	K.N. Panicker
IOCC	Hari Desta
LEPRA	Rachora Kuman, Rajni Kant Singh, Paul Watson
LSTM CNTD	Louise Kelly-Hope (Chair), Brent Thomas
Mectizan Donation Program	Joni Lawrence, Yao Sodahlon
MITOSATH	Francisca Olamiju
MoH, Kenya	Stephen Mwatha
NaPAN	Deveje Asefe
Nigeria, Public Health	Chinyene Mkaga
NTDSC, Atlanta	Charles Mackenzie
RTI	Daniel Cohn, Fikreab Kebede (Ethiopia), Dhampal Ramon
Sightsavers	Louise Hamill
UFAR	Daniel Shungu
WHO ESPEN	Honorat Zoure

*Note. Compiled from the paper lists circulated during the meeting [please notify the Chair if your name does not appear, or there are any errors with your name and/or affiliation]*

## Final Agenda

### LF NGDO Network Meeting Addis Ababa, Ethiopia - 26<sup>th</sup> September 2018

9.00-12:30	Session	Presenter
9.00-9.40	1. Welcome & updates from LF Network Chair	Louise Kelly-Hope
	2. Status of Global Elimination of LF 2017	Slides from WHO - Jonathan King
	3. Mectizan Donation for IDA countries	Yao Sodahlon
9.40 – 10.30	4. GAELF update	Charles Mackenzie / Joan Fahy
	5. Updates from subgroups - LF/Oncho subgroup - MMDP/DMDI subgroup - London Declaration Scorecard group	Charles Mackenzie Linda Lehman / Jan Douglass Francisca Olamiju / Brent Thomas
10.30-11.00	COFFEE BREAK	
11.00 – 12.30  <i>5-7 min per partner + 3 min Q/discuss</i>	6. Rapid Fire updates from selected partners (achievements /current issues) - CBM - Footwork - HKI - LEPRA - RTI - Sightsavers - Indian Network	Johan Willems Gail Davey Zeina Sifri Paul Watson Daniel Cohn Louise Hamill KN Panicker
	General Discussion / Future of the Network	All

1	<p><b>WELCOME AND UPDATES FROM LF NETWORK CHAIR (Louise Kelly-Hope)</b></p>
	<ul style="list-style-type: none"> <li>• Louise Kelly-Hope welcomed the participants to the meeting and introduced Brent Thomas and Joan Fahy as rapporteurs.</li> <li>• The important links between the Global Alliance to Eliminate Lymphatic Filariasis (GAELF) and the Global Programme to Eliminate Lymphatic Filariasis (GPELF) were highlighted.</li> <li>• LF NGDO Network - Terms of Reference (ToR) update <ul style="list-style-type: none"> <li>○ To-date, the LF Network has had seven Chairs with a 1-year term. Going forward the Chair would be for a 2-year term, with the decision based on the LF Network survey feedback in April 2018.</li> <li>○ Maartje Pronk from Lepra was introduced as the incoming Vice Chair (although she was unable to be present at the meeting).</li> </ul> </li> <li>• LF NGDO Network sub-group leads were introduced. The Chair thanked those stepping down for their contributions and welcomed the new leads. <ul style="list-style-type: none"> <li>○ Onchocerciasis - Charles Mackenzie</li> <li>○ MMDP [DMDI] - Jan Douglass, replacing Linda Lehman</li> <li>○ London Declaration Score Card – Franca Olamiju (with support from Brent Thomas), replacing Molly Brady</li> </ul> </li> <li>• LF Network Survey 2108: A summary of the survey results was presented, highlighting key themes for future NNN and LF Network meetings (also available in the survey summary report circulated to the member list).</li> <li>• NDGO Partner matrix. A map showing where partners were working and the range of MDA and MMDP activities being conducted was presented. The final NDGO Partner matrix is due to be finalised by December 2018.</li> </ul>
2	<p><b>GLOBAL PROGRAMME TO ELIMINATE LYMPHATIC FILARIASIS 2017 update for the LF NGDO Network Meeting (Jonathan King)</b></p>
	<p>Chair presented on behalf of Dr J. King who could not attend the meeting.</p> <ul style="list-style-type: none"> <li>• The Global Commitment, WHA 50.29 and GPELF goals were highlighted.</li> <li>• MDA topics presented included - the scale-up of LF MDA 2000-2017; GPELF Progress and MDA status of countries in 2017; proportion of IUs that have completed TAS; New guidelines for LF MDA (in countries currently using DEC +ALB); IDA implementation lessons learned.</li> <li>• MMDP topics presented included – the basic package of care, current status on MMDPP monitoring 2017; importance of MMDP reporting; and new LF MMDP training package</li> <li>• Final slide was a call to action <ul style="list-style-type: none"> <li>○ <i>Support implementation of IDA where warranted</i></li> <li>○ <i>Support enhanced focus on quality MDA for all remaining rounds;</i></li> <li>○ <i>Enable NTD programmes to monitor patients and available care by IU which will be required for validation</i></li> <li>○ <i>Enable primary health-care systems to deliver recommended basic package of care for MMDP</i> <ul style="list-style-type: none"> <li>▪ <i>Integrate where feasible: skin NTDs, mental health and disability programmes</i></li> <li>▪ <i>Build capacity</i></li> </ul> </li> </ul> </li> </ul>

3	<b>MECTIZAN DONATION FOR IDA COUNTRIES (Yao Sodahlon)</b>
	<ul style="list-style-type: none"> <li>• Yao Sodahlon reported that Merck announced it will donate to eligible communities: <ul style="list-style-type: none"> <li>○ Up to 100m Mectizan treatments annually to 2025 beginning in 2018;</li> <li>○ Requests to be reviewed and tablets allocated through a transparent and fair mechanism to be established by the Mectizan Donation Program (MDP) and its Mectizan Expert Committee (MEC)</li> <li>○ Approved tablets will be shipped and delivered to the specified warehouse in recipient countries free of charge</li> </ul> </li> <li>• Mectizan Donation guide for IDA has been developed with stakeholders and available on MDP website. It has also been shared with all WHO regional offices. <a href="https://mectizan.org/news-resources/mec-guide-for-donations-of-mectizan-in-ida-countries/">https://mectizan.org/news-resources/mec-guide-for-donations-of-mectizan-in-ida-countries/</a></li> <li>• Country eligibility to receive Mectizan for IDA includes an assessment of i) epidemiological eligibility, ii) political commitment and iii) ability to plan and implement IDA with high coverage. Application same as JAP.</li> <li>• 2018 donations for IDA include WPRO- 5 countries; SEARO -1 country; AFRO – 1 country and EMRO – 1 country</li> </ul>
4	<b>GAELF UPDATE (Charles Mackenzie and Joan Fahy)</b>
	<ul style="list-style-type: none"> <li>• The activities of GAELF and Steering Group were presented. Charles Mackenzie spoke of the successes of GAELF10 in India.</li> <li>• Joan Fahy provided information on the GAELF website and noted that GAELF welcomed publications and blogs for uploading.</li> <li>• The potential for a follow-on London Declaration meeting was noted for 2020, which may impact on plans for GAELF11.</li> <li>• A call for to hear more from civil society and greater local profile in endemic countries was noted.</li> </ul>
5.	<b>UPDATES FROM SUB-GROUPS</b>
	<b>MMDP/DMDI (Linda Lehman [Jan Douglass])</b>
	<ul style="list-style-type: none"> <li>• The purpose of the NNN MMDP/DMDI Working Group was detailed including the DMDI Task Groups TG-1 Indicators and Mapping; TG-2 Interventions; TG-3 Mental Well-being and Stigma and TG-4 Participation, Inclusion and Human Rights.</li> <li>• The results of a survey from 14 organization was reported. The main challenges and what was needed to develop MMDP/DMDI activities was presented, which included, for example, lack of funding, resistance from groups to collaborate, lack of IEC materials, weak peripheral health systems.</li> <li>• It was suggested that the MMDP/DMDI sub-group needed think and present more about how LF care can go beyond the ‘minimum package’</li> </ul>
	<b>LONDON DECLARATION SCORECARD (Franca Olamiju and Brent Thomas)</b>
	<ul style="list-style-type: none"> <li>• NTD Scorecard update - The first 5 versions of the old scorecard have been replaced following a review in 2017; it contains two annual tools <ul style="list-style-type: none"> <li>○ Impact dashboard: quantities data from WHO – new and current partners</li> <li>○ Action framework: qualitative information from partners/LF community to ID gaps, bottlenecks and actions within 3 pillars (Enabling Environment, Strategy, and Public Health Intervention), 11 components and 32 requirements.</li> </ul> </li> <li>• Impact dashboard under development, awaiting 2017 data from WHO.</li> <li>• Action framework: <ul style="list-style-type: none"> <li>○ Contains three steps</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ Disease specific consultation: Currently ongoing. AF sent to LF partners to provide feedback.</li> <li>▪ Cross-disease dialog: Meeting planned for 10<sup>th</sup> and 11<sup>th</sup> of October in Geneva with WHO and all disease groups to prioritize areas for collective action and advocacy.</li> <li>▪ Action and Advocacy: Partners and disease communities follow-up on prioritized actions and messages. <ul style="list-style-type: none"> <li>○ Shared with 46 LF partners, current responses are low with only 9 partners responding.</li> </ul> </li> </ul> <ul style="list-style-type: none"> <li>• The Action Framework will be shared with partners once complete.</li> </ul>
6	<b>RAPID FINE UPDATES FROM SELECTED PARTNERS</b>
	<b>CBM (Johan Willems [Martin Kollman])</b>
	<ul style="list-style-type: none"> <li>• CBM’s mission was presented and the support and achievements in DRC, Nigeria, South Sudan and Central Africa Republic were highlighted. In DRC and Nigeria, a wide range of activities were being supported, including for example, MDA implementation, planning meetings, drug logistics, training of health zone staff, nurses, teachers and CDDs, morbidity case reporting.</li> <li>• Operational research on LF related stigma and mental wellbeing in Jos, Nigeria was described, highlighting a need to address this important topic</li> </ul>
	<b>FOOTWORK (Gail Davey)</b>
	<ul style="list-style-type: none"> <li>• Footwork’s purpose and goals, a description of podoconiosis, the 6 countries where Footwork was working were presented <a href="https://podo.org/">https://podo.org/</a></li> <li>• The 2017-18 main achievements included securing funding from Izumi for 2 years, completing country-wide mapping in Rwanda, preparations in Uganda and Burundi, and launching a NIHR funded programme of research</li> <li>• Potential challenges included the current situation that the management of podo is included in the morbidity management of LF. This is welcome, but leaves gaps e.g. need to promote regular use of shoes, and lack of co-distribution in some countries e.g. Rwanda (no LF, but podo endemic)</li> </ul>
	<b>HKI (Zeina Sifri)</b>
	<ul style="list-style-type: none"> <li>• A description of the USAID-funded MMDP project supporting high quality LF interventions using preferred practices and development of innovative strategies (when needed) to meet elimination goals was presented.</li> <li>• Interventions for lymphoedema included lymphoedema management training curriculum, burden assessments, health facility assessments, WHO LF MMDP training with a total of 857 health staff trained as trainers, 1237 community workers as caregivers and 1809 patients trained in selfcare.</li> <li>• Interventions for hydrocoele included the hydrocoele surgery training FASTT, burden assessments, obstacles to surgery, surgery and follow-up.</li> <li>• Hydrocoele trainings included 3 Master FASTT trainers, 17 national surgery trainers, 127 surgical care providers, 336 health staff for support.</li> </ul>
	<b>LEPRA (Paul Watson)</b>
	<ul style="list-style-type: none"> <li>• Lepra’s mission was presented along with a description of LF activities in India, Bangladesh and Mozambique, which included MDA support, vectors control, capacity building, case-finding, self-care training, psychosocial support, complication management, and support for hydrocelectomies.</li> </ul>

	<ul style="list-style-type: none"> <li>• Best practices in LF-leprosy care including self-care group formation and support for capacity building of health staff were presented drawn from work with Lepra, NLR and effect:hope. The benefits from both the management and beneficiary perspectives were highlighted.</li> <li>• Key lessons learnt in LF-leprosy care were summarised and included the importance of engaging with local health staff in project design and implementation, work with local leaders and family members, and strengthen the evidence base through research, mapping, data collection.</li> </ul>
<b>RTI (Daniel Cohn [Molly Brady])</b>	
	<ul style="list-style-type: none"> <li>• RTI International’s mission statement and Envision goal were presented, highlighting involvement of USAID MMDP Project managed by HKI (implemented by RTI in Ethiopia) and END Fund support (Senegal).</li> <li>• Working in 19+ countries with activities supported by 8 implementing partners, including, for example, policy development, strategic planning, mapping, procurement, capacity strengthening, social mobilisation, dossier development, operational research</li> <li>• Key achievements include 88% districts effective epi MDA coverage; pilot of electronic data collection, implementation of field training module, multi-country analysis for pre-TAS and/or TAS, dossier development for 6 countries with Vietnam’s submitted</li> </ul>
<b>Sightsavers (Louise Hamill [Phil Downs])</b>	
	<ul style="list-style-type: none"> <li>• Sightsavers support for LF activities in Cameroon, Cote d’Ivoire, DRC, Guinea Bissau Guinea, Nigeria, Uganda including MDA, patient care and M&amp;E were presented.</li> <li>• Main achievements included patient care activities successfully underway in 4 states of Nigeria, 4 districts in Uganda and 2 provinces in DRC and training/retraining of 13,317 health workers, 120,936 CDDs and 23 hydrocele surgeons</li> <li>• In Guinea-Bissau two regions were remapped with Cacheu region found to be endemic and Toubali region not</li> <li>• In Nigeria, 203 local government areas (LGAs) supported for LF MDA with a map presented highlighting the complex combination of NTD co-endemicity</li> <li>• Main challenge included the instability in 2/3 districts supported in Cameroon likely to impact on MDA delivery.</li> </ul>
<b>Indian Network (K.N Panicker)</b>	
	<ul style="list-style-type: none"> <li>• The Indian Network for NTD is was an amalgamation of different institutions and health care professionals which provide MMDP/DMDI messages and care to endemic communities using the WHO guidelines.</li> <li>• A project on “Morbidity Management, Disability Prevention and Rehabilitation of Socially abandoned, Poverty stricken Filarial patients”: Kerala, India was presented.</li> <li>• Over 4200 disabled, disfigured, aged patients are expected to benefit. The project is supported by local corporates like Chittilipilly foundation.</li> <li>• Rehabilitation an important factor, and support to those suffering from psycho-social problems, and who are older and considered a burden on families. Footwear available.</li> <li>• A new cooperative movement developed to help patients become more independent - ‘I can stand on my own legs’ – to assist them to get work, for example, in roadside kitchens, rearing of poultry and tailoring.</li> </ul>

*Note. Name in [square brackets] indicates person contacted to present but unable to attend the NNN or the LF Network meeting due to a conflict with the session.*