Ethiopia Coordination Meeting
Monday 18 March 2019, Greenville

Present
DFB – Alex Jaucot (Chair) & Pierre Umba (Observer)
ALM – Darren Schaupp (DS)
DAHW – Burkard Kömm (BK), ILEP Country Coordinator
Effect:hope – Maneesh Phillip (MP)
TLMI – Brent Morgan (BM)
ILEP – Monty Mukhier (MM)

ILEP Members involved in country
ALM (representative based in Kenya), DAHW, TLM (Representative based in DRC), effect:hope (support through TLM), NLR (support LPEP through DAHW).

SWOT analysis (Burkard Kömm)
Burkard Kömm presented a SWOT (Strengths, Weaknesses, Opportunities, Threats) analysis of the leprosy situation in Ethiopia.

Strengths:
• A leprosy stakeholder platform which meets quarterly has been in place since 2013, it focuses on information exchange and coordination of efforts. Members are National association of persons affected with leprosy, GLRA and TLM-Ethiopia.
• A leprosy Technical Working Group exists and is coordinated by the Federal Ministry of Health. It consists of experts from ILEP members in the country and the national leprosy affected associations.
• The two mechanisms mentioned above have conducted a country wide leprosy mapping, increased public awareness on leprosy, enhanced political commitment and allowed associations of people affected by leprosy to represent themselves at all levels.

Weaknesses:
• The leprosy stakeholder platform and the Technical Working Group do not meet regularly.

Opportunities:
• Existence of new leprosy initiatives like Post Exposure Prophylaxis (PEP), The outcome of which could influence future policy and direction of the government.
• Adoption of the new PEP strategy by WHO.
• Creation of GPZL could bring stakeholders together even more.
• Existence of a national leprosy strategy.
• GLRA’s office in Ethiopia has one of its strongest administrative teams.
Threats:

- Leprosy is underfunded and lacks attention both nationally and internationally.

Overview of TLM activities and challenges (Brent Morgan)

- Most of TLM’s funding in last 20 years has been through the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), who have now built themselves into a national voice and receive funds from several donors.
- Main activity is a Leprosy rehabilitation project which started in 2017 and is expected to end in 2021 (100,000 pounds a year).
- Good network of persons affected which could be mobilised for all sorts of things. However, there is concern that ENAPAL is more focused on rights (stigma, discrimination) rather than detection, treatment and prevention disabilities. Would like for them to be more involved.
- Main challenges are that the technical working group does not meet regularly (only met once in 2018) and the 70/30 rule which is difficult to manage as 70% of funds must go to programs and 30% to administration.
- In recruitment process for a new country director of Ethiopian nationality.

Solutions to improve Coordination

DAHW and TLM managed to quickly find direct solutions to several issues including:

- Strengthening relations
  i. It was suggested that DAHW’s Ethiopian representative should be involved in TLM’s recruitment process as it could help with future cooperation if the two representatives already knew each other and had a strong relation.
  ii. BK and BM will consider travelling to Ethiopia together to learn more about each other’s projects and improve cooperation between their country offices.

- Improving coordination
  i. ILEP members will work towards achieving the goals of the national leprosy strategy.
  ii. ILEP members will try to ensure that both the stakeholder platform and the technical working group meet regularly. Meetings should be called by the ministry of health, but ILEP Members will support facilitating.

Follow-up discussions

DS informed the participants that ALM is planning to do AIM mapping in Ethiopia and would like for it to be joint between NTD and leprosy departments. However, there is a lack of funds, it would cost around 120,000 USD to map all NTDs. He also mentioned that currently ALM does not have any active projects or research in Ethiopia and that they proposed to pilot LepVax but their proposal was rejected.
BK mentioned that there is a need for new approaches that do not follow conventional means and suggested that since all endemic districts have been mapped ILEP members should consider doing a study, split the districts in half and apply different approaches to see which works best. He also suggested that as transmission occurs before diagnosis, the two approaches should be preventive like LPEP or LepVax.

**Key Reference facilities and sustaining leprosy expertise (knowledge and skills)**
The discussion then shifted to key reference facilities and how leprosy expertise could be sustained. BK mentioned that there were two major facilities in Ethiopia:

i. ALERT medical facility which used to be very active in training EU and Indian doctors.

ii. Bisidimo hospital which is in the East and specially trained dentists for leprosy.

It was agreed that ALERT is not as active as it once was and there is a need to maximise its training services as it would help with sustaining leprosy expertise. However, it was mentioned that it is currently hard to gain experience as the number of new cases with complications are low and they are spread throughout the world.

It was mentioned that it would be cheaper in the long run to consolidate expertise in excellence centres rather than training experts in different places and a suggestion was made to consider setting up regional leprosy excellence reference centres and sending all cases with complications in east Africa to ALERT. If all patients go to the same centre, then doctors will be exposed to more cases per year and gain more experience which would contribute to sustaining expertise. However, concerns were raised around difficulties that people affected would encounter to issue passports, obtain visas and if governments would allow free travel and treatment considering the stigma related to leprosy.

It was suggested that for issues that require quick interventions (e.g. diagnosis and management of leprosy reactions) new technologies for e-learning and remote diagnosis, as well as mobile clinics to bring services to the patients should be considered. Several examples were mentioned including setting up a virtual investigation room from which experts would be able to examine patients using virtual reality glasses, using Whatsapp and other digital platforms to send images that could be used for remote diagnosis.

**Action**
The participants agreed that a proposal should be made to the Members’ Assembly to form a small ad-hoc work group, including an expert in digitalisation, to investigate new technologies and innovations for e-learning and e-diagnosis. The group should preferably be formed before the ILC in September so that initial feedback can be given at that time and before the finalisation of the 2020 action plans and budgets.