

## Leadership Team Meeting Teleconference

August 2019

### Participants

#### Leadership team members and guests

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Alice Cruz, UN Special Rapporteur (observer)
- Zaahira Gani, Project Manager, Novartis Foundation
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen

#### Secretariat

- Jessica Cook, Communications Director, Global Partnership for Zero Leprosy
- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Christine Fenenga, Operational Excellence Coordinator, Global Partnership for Zero Leprosy
- Andie Tucker, Communications Specialist, Global Partnership for Zero Leprosy

#### Invited but unable to attend

- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Jan van Berkel, Chair, Executive Group, Leprosy Research Initiative
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)

- I. **Welcome from Leadership Team Chair Bill Simmons**
- II. **Communications update (Andie Tucker, Jessica Cook)**
  - Nepal: Andie had the opportunity to go to Nepal for the country review in July to act as the on-site communicator. She was able to document the review and capture important stories and videos interviews from key stakeholders on the ground, including partner organizations working in leprosy, and persons affected. This is our first original visual content for GPZL and it will be used on the Global Partnership for Zero Leprosy's (GPZL) website, in printed materials, and for upcoming digital campaigns.
  - Toolkit progress: The architecture of the toolkit is complete and we're adding tools as they come in from the operational excellence working group members.
  - Upcoming events: We are creating new materials for ILC that will be leveraging photos and visuals from Nepal. We will be represented at NNN in several sessions, including as part of a cross-cutting working group evaluating successful partnerships in NTDs. Geoff will represent the GPZL on this on panel, which includes a representative from ITI, and someone else from HIV or another disease outside NTDs. We will also have a rapid-fire presentation from Rabindra about the implementation of the country model in Nepal. GPZL and ILEP are sharing a booth this year.
  - WHO ESPEN Meeting: The partnership hosted a side meeting on the country model at the WHO ESPEN Meeting in July. The purpose of the side meeting was to inform country managers about country model, and specifically for African managers to participate and be informed. The session included a panel presentation and a Q&A. The presenters were leadership team members Benedict, Christian, and Geoff.
    - Geoff: We pleased with the number of people that attended, with about 40 in the room. It was very good to have Benedict and Christian presenting as they are highly-regarded experts. Christian has a good rapport in francophone Africa, and Benedict was also talking with his peers. The questions from the session were interesting. It was particularly interesting to have questions about the role of the partnership vs the role of WHO. We haven't focused too much on this question, but it seems to be front of mind for National Leprosy Programme Managers. I didn't know everyone in the room, and we didn't get a list of everyone in attendance. Benedict and Christian could probably identify who we should target from this meeting.
    - Jessica: Angola submitted an expression of interest on our website to explore GPZL conducting a review of the programme.
    - Erwin: I am surprised that Angola would express interest for review because they just had one a few months ago. There was also a mini review in Cote d'Ivoire in July.

- Geoff: To what extent does a country like Angola see GPZL as a global collation that includes WHO, or entirely separate from WHO?
- Christine: I will talk about this more in my presentation later on this call.
- Bill: What do we do with countries that make inquiries on their own, apart from WHO? We need to find ways to make sure we're more effective at working together.
- Erwin: Contact between WHO, countries, and GPZL will help us know when reviews are upcoming.

### III. **Research Agenda Manuscript (Courtenay Dusenbury)**

- The proposed commentary for Lancet has been accepted. Cairns Smith is writing that document and will have a draft shortly. Sub group reports will be published in Leprosy Review, with a commentary from David Scollard. His commentary will be linked to the commentary in Lancet.

### IV. **Resource Mobilization Update (Courtenay Dusenbury)**

- MacArthur 100 Million & Change: This application was submitted yesterday. We sent everyone a short version of the questions but the application is complex; I'll send a PDF file of our final application. We can take the various parts of this proposal and use them for other donors. We're happy to advise people on what other donors they can approach.
- Audacious challenge: This is a short application. We'll send you a draft of what we suggest submitting for this.
- We're starting to plan for the Manila meeting, where we'd like to discuss a three-year strategic plan, and what types of targets and long-term timeframe we will need. Another issue that's been identified for conversation in Manila is the role of WHO and GPZL in country reviews and beyond. We would also like to talk about resource mobilization, the election of two global members, and the election of a representative from Brazil.
- UTC advisory committee nominee: During the last call we discussed nominating someone from GPZL to the UTC advisory board. Wim van Brakel has been nominated. We had inquiries from several LT members about also nominating a person affected by leprosy. If the Leadership Team agrees, we'll ask IDEA to put forward a candidate to be submitted, with Wim. **Leadership team agreed.**

### V. **Operational Excellence Working Group (Christine)**

- Nepal country review and roadmap (7-17 July 2019): I'd like to brief you about the first GPZL country mission in which we worked closely with the Ministry of Health and Population (MoHP) in Nepal, the WHO, and many local stakeholders on an in-depth

- country leprosy review, including a stakeholder review meeting and the creation of a roadmap. I will go over the: 1. Process, 2. Results /some Key Findings, 3. Lessons learned, 4. Next steps.
- **Process:** This took place from 7-17th July. Christine went to Nepal two days before to have meetings with several people at the Ministry. The GPZL participated with two members of the Secretariat: Christine, who had been actively involved in the planning of this mission, and Andie, who joined this mission to capture important stories and visual content. In addition, GPZL contributed three experienced reviewers, selected from the Operational Excellence Working Group: Dr. Silitham Sermrittirong (Ministry of Health Thailand), Dr. Anuj Tiwari (Erasmus University) and Dr. Liesbeth Mieras (NLR). Novartis' Ms. Zaahira Gani and her Nepali colleague, Mr. Prashat Deshpande participated in the stakeholder review meeting and roadmap planning. A representative from Sasakawa Foundation was unfortunately not available to join the team. The overall team lead was Dr. Hany Hasan Ziady from Egypt. He is currently an independent consultant but was a long-term employee of the WHO. In addition to these external team members, there were two other WHO reviewers, 2 dermatologists from the Ministry of Health and Population (MoHP), and local stakeholders facilitating the team.
  - The program included one prep day, in which program and tools were presented, five days of field work in three provinces by three separate teams (team three also conducted field work at the central level, the stakeholder review meeting, and the roadmap planning), and three days of report writing. It also included a day-long LPEP meeting, a two-day long stakeholder review meeting (involving 32 people, including persons affected), a half-day of roadmap planning, a pre-presentation of the review findings, and concluded with a dissemination meeting with Ministry of Health and Population (MoHP) and stakeholders.
  - **Results:** We learned a lot during this first mission. We delivered a joint presentation of key results during a well-attended dissemination meeting at the Ministry of Health and Population. The presentation was well received, and evoked words of appreciation and a few questions. One question raised by a person affected by leprosy concerning discriminatory laws was immediately responded to by the Minister, and she told us her Ministry would act to address the law. We also delivered a two-page brief to the Ministry, which you can find in the report annex. The report of the mission is in its final drafting stage. The draft stakeholder review report has been checked and commented on by participants and can also found in the annex.
  - **Key findings: Indicators 2018**
    - Overall prevalence rate is 0.99/ 10,000 population nearing the reversal of Nepal's elimination status (as public health problem). Province 2 reported

highest new cases: 19.36 per 100,000 and prevalence rate 1.63 cases per 10,000 population.

- Total number of 3249 new cases were detected; 56% multi bacillary (MB).
- Proportion of children among new cases is around 7% (202 cases), which denotes recent transmission.
- Grade 2 Disability rate around 5/million population (133 cases), which denotes delayed detection.

In the in-depth review report you will find more details about these statistics. Many of the issues discussed relate to the recent restructuring/decentralization of the Nepali administration. The district level has been more or less removed from the government structure and their responsibilities have been transferred to the 753 municipalities in the 7 provinces. This has resulted in a loss of data and has led to critical challenges in monitoring progress. Health coordinators are overburdened at the municipality level, and insufficient supervision and skills at local level prevent accurate diagnosis and treatment (including reactions). Staff still at district level is frustrated because there is no clarity about responsibilities, but in general, there is a lot of motivation at various levels to make it work.

- Urgent actions: considering the major restructuring/decentralization of last year
  1. Data management improvement. There is a need to appoint focal points for data reporting (i.e. statistical officers) while staff at all levels need to be trained to manage data (report reference: 1.2.1). Innovative solutions should be considered to support the capture of relevant data (2.3.2.) At national level, a statistical officer is needed at LCDMS.
  2. Establish detailed insight in leprosy HR and availability of all leprosy services. This can be achieved by mapping of all districts (i.e. HR and skills, G2D, types of services (3.2.2).
  3. Generate a detailed financial analysis (including public and non-public partners) to determine and map the current expenditure distribution funding gaps and solutions for the program (1.1.3).
- Activities to improve and or scale:
  - There is a need to scale and improve surveillance (3.2.1.), active case finding, and verification, and integrate this as standard program activity. Chemoprophylaxis and contact screening, which is only available in some districts, should be accessible for all, particularly in high endemic districts. (3.1.1.).

- Staff will need to be trained to scale these activities. Also, there is a need to evaluate the trainings. New trainings should include innovative methods such as e-learning and standardized modules (1.4.1).
- All of these activities will first require commitment and support from the central level. Secondly, they will require close collaboration between all national and international stakeholders through the setting of harmonized joint priorities and targets. (2.1.5).
- Lessons learned:
  - Awareness: Although preparations for this mission started early (during the January development of joint stakeholder review tool WHO/GPZL we jointly developed Terms of Reference, which went through the selection and approval of reviewers), the awareness of the GPZL objectives was not well understood by all levels in the MoHP Nepal and WHO. GPZL did send an official letter to the higher level at the MoHP but it is clear this will need more attention in future reviews.
  - Communication and partnership collaboration challenges: Roles may need to be more clearly defined for the next review.
  - Organization/efficiency: The field teams were large and therefore not optimally efficient. It was often hard to conduct interviews effectively with so many people around. Local stakeholders had to use their valuable time and resources for long field visits. Although these are maybe standard procedures of country and WHO, we question is whether this is the most effective way we could conduct these types of reviews.
  - The Stakeholder review tool worked to define the current status of the program and to identify priorities. The questions were clear and, besides some few instances in which some explanation needed to be given, did not need adjustments.
- Next steps: Collaboration and communication
  - We should strive for better communication and awareness raising at higher level within WHO (Delhi and Geneva) and with host countries in preparation for the country reviews and roadmaps. Support from the leadership team is also very welcome. Dr. Taka has already visited the RD SEARO in Delhi but we will also need to create further awareness at WHO/NTD.
  - GPZL should intensify communication with ILEP partners. They can help strengthen our work with MoHP.

- We should improve communication with WHO about division of responsibilities. Does GPZL team need to spend weeks in the field to collect standard data, or should we do shorter field visits, by using more existing reports and data at national level, to analyze the main issues and explore further during the field visits?
- We also need to have a discussion on the plans of the NTD roadmaps that have been high on the agenda of the WHO. What does this mean for our country model, in which we also envision a roadmap? Should we change the name of this plan to prevent confusion?
- We have to aim for timely approval of agreed upon Terms of Reference, program, and tools, and not change these shortly before a mission. This will help us agree on a division of tasks and will help external reviewers know their roles and how to appropriately prepare.
- Next steps for Nepal:
  - The reports will be disseminated. As agreed during stakeholder meeting LCDMS (Dr. Rabindra), will solicit volunteers to establish core group to continue work on the Roadmap. This group will include stakeholders and WHO Nepal, and will possibly align with NLR Nepal- led fundraising efforts who will liaison with GPZL partners on how to ensure funding.
  - Christine will travel to Nepal for MoU and to help developing a proposal for immediate support.
  - Results will be presented at the International Leprosy Congress in September and at the Liverpool NNN meeting.
- Discussion:
  - Bill: For the partnership and the leadership team we now understand the difference between information flow and a unified understanding. I think what we've seen is that we engaged in a lot of information flow, but there wasn't a unified understanding as to what was taking place. This creates misalignment that results in a gap in expectations. We have a lot of lessons learned from this.
  - Courtenay: It's clear that we need to work out our roles with WHO. Everyone is committed to doing that. They're different roles. It's not surprising that we've come to a point that we're trying to work this out. A way the partnership can really add value is in raising money and bringing together partners. Christine has put so much work into the country model, with over 180 people contributing to this. It was great to see this being tested in country. At the secretariat we're developing a country plan for Nepal with WHO. We'll be looking for resources for

that plan. This will help us show the added value of GPZL, bringing together funding and partners to move Nepal forward.

- Erwin: Where does the roadmap fit into this process? Health sector planning is starting in 2022, so this review is a mid-term review. It will help us modify the current strategy, but the roadmap will not be a stand-alone document that will be funded on its own, that will be the five-year strategy.
- Christine: The roadmap should be a guiding document that can be used to guide conversations with the ministry about filling gaps.
- Alice: Congratulations Christine on the success of this mission. We need to raise awareness at both a high level *and* local level.
- Morocco country review and roadmap: This review will take place on 14-21 Oct. 2019. We are working with the National Leprosy Programme Manager to establish the Terms of Reference for this review.

#### **VII. Updates and comments from Leadership Team members**

- Geoff: We won't have the full set of ILEP meetings in Manila but the technical commission will listen in on sessions and then tell ILEP at the end what was important and what they should know about. I've been involved with the surveys by McKenzie on the NTD roadmap, primarily on the disease management and disability management. Watershed moments from this meeting today: the pilot in Nepal, MacArthur submission are particularly key moments in the life of GPZL.
- Benedict: Good to hear about report from Nepal. The lessons learned will give us an opportunity to improve moving forward.

***Meeting adjourned.***