

Leadership Team Meeting

5 November 2020

Participants

Leadership team members and guests

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Jan van Berkel, Chair, Executive Group, Leprosy Research Initiative
- Gangadhar Sunkara, Senior Global Program Clinical Head, Novartis
- Rao Pemmaraju, Technical Officer, WHO Global Leprosy Programme (observer)
- Amar Timalina, President, International Association for Integration, Dignity and Economic Advancement (IDEA) Nepal
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (guest)
- Mathias Duck, Chair of ILEP Panel of Persons Affected by Leprosy
- Alice Cruz, UN Special Rapporteur (observer)
- David Blok, Researcher and Mathematical Modeler in Infectious Diseases, Erasmus MC
- Sundeep Chaitanya, Director of Research and Innovation, American Leprosy Missions

Secretariat

- Bill Gallo, Secretariat Director, Global Partnership for Zero Leprosy
- Andie Tucker, Project Manager, Global Partnership for Zero Leprosy
- Mondie Tharp, Project Manager, Global Partnership for Zero Leprosy
- Caroline Cassard, Communications Specialist, Global Partnership for Zero Leprosy

Invited but unable to attend

- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program
- Mark Alexander Rogers, Senior Global Program Head Neglected Tropical Diseases, Novartis
- Rekha Shukla, Joint Secretary, Ministry of Health and Family Welfare, India

I. Welcome: Bill Simmons

- **Bill Simmons:** Welcome to our monthly call. Welcome to David Blok and Sundeep, who we haven't seen in a while.

II. Next steps from LT bi-annual meeting: Andie, Mondie, and Bill Gallo

Meeting Date	Action item	Next steps
19 Oct	Gather more information from 2020 NLPs about current situations on the ground in each country to better understand how to move forward	Currently meeting with countries
	Rethink the country model for remote implementation, with a focus on working closely with our implementing partners in-country	Secretariat will make recommendations to budget and workplan working group, based on conversations with NLPs in partner countries
20 Oct	Convene donors as a small group to develop and draft a budget and work plan by early December	First meeting has been scheduled, draft budget and workplan to be discussed in next LT meeting
	Update the charter with edits agreed upon during this meeting	Charter has been updated
	Continue discussions about persisting governance questions with governance WG	Identify potential consultants November/December 2020; Convene group in January 2021
	*Clarify GPZL's collaboration with partners and members	Position paper about partners
	Open applications for the open LT positions	To be completed in March 2021
21 Oct	Begin landscaping of current research in the priority areas outlined in the research agenda prioritization work	TOR for this work has been drafted, currently under review

- **Alice:** I had a meeting arranged by TLM with a national group of persons affected in Bangladesh. They told me something that should guide our work. I asked them, What would you ask your government to do? They replied, we want to get to a point where we don't need to ask for our rights to be recognized. This means being impactful.

I want to share concerns from people on the ground regarding GPZL. The Partnership needs to show its added value on the ground, or we lose credibility. Persons affected, NGOs, public health managers, and health workers ask, What is the Partnership doing? They don't know. We need to take action even though we are not 100% sure that we are doing the right thing.

The situation in Brazil regarding lack of MDT is serious. As a Rapporteur, I receive complaints and communicate with the government. But GPZL needs to not only move forward but also show people what is being done with concrete messages. We are discussing models while very basic needs such as MDT are not being met.

- **Maarten:** Do you have examples of what people expect from the Partnership?
- **Alice:** People expect material support and a platform to which people can reach out so their concerns can be taken to those who have responsibility on a certain matter. Leprosy Programme Managers in Brazil have included almost all of my recommendations to eliminate stigma in their planning. Brazil has a strong population of persons affected by leprosy. The Partnership should develop a mechanism of accountability and should monitor progress to then communicate that to people on the ground. It should not be a small group of privileged people.
- **Ganga:** Novartis and WHO have been doing this for 20 years. The pressure has to be on both Novartis and WHO if the clinic is not getting MDT. If we both take care of this, then why does the Partnership have to do something?
- **Alice:** People do not understand what is going on at the international level. That is why communication is so important. People have been looking at the Partnership as the leadership regarding leprosy at the international level. We need to assume that people do not understand the responsibilities as we do.
- **Ganga:** From the MDT point of view, I want to get to the patient level and solve this problem. Secondly, if we address all comments about an elite group of members, we miss the main mission of what we want to do with the research agenda and operational agenda. But I do acknowledge that we need to have stronger communications.

- **Alice:** We have to show impact at the country level.
- **Bill Simmons:** To summarize: the Secretariat could help publicize in different ways. Hearing from Alice what people are listening to can inform headlines.

III. Recap of Global Leprosy Strategy (GLS) consultation: Erwin Cooreman

- **Erwin:** The consultation meeting is part of a process. We received information that we will incorporate in the final strategy. We had 350 to 400 participants for each day. All high-burden countries participated. We received feedback from the ground. There was no major dissent or disagreement. It is mostly fine-tuning. We will finalize it in the coming weeks. There will not be further consultation. We plan to launch it around World Leprosy Day. It should not be difficult to get it approved by senior management.

The last strategy had an operational manual and the M&E guide. The operational manual was the least used. I'm not sure if it was valuable for the countries. We do not plan to have a stand-alone operations manual, as technical guidance will be published as part of WHO's normative work. The Strategy will be our main guidance document for the next 10 years.

It might be good to have an implementation plan. Ten years may be too long for a single plan for implementation. Maybe we could have two plans, five years each. It could be developed in part by the Partnership. This would give visibility to the Partnership and would be something more tangible and manageable than a broad 10-year strategy. A similar approach is taken by the TB community.

- **Cairns (chat):** I think it would be helpful to ask Erwin to inform the Partnership about MDT distribution.
 - **Erwin:** We had monthly virtual meetings with headquarters and all regions yesterday and received the same feedback. Production and transportation are issues. WHO should take part of the blame. We only respond to countries when there is a query from a country. 2020 was characterized by multiple problems including drug-related as well as due to COVID; the first one is generally beyond WHO's control while mitigating COVID situations should now be effective. There is a reputation risk for WHO and Novartis. The MDT programme has been successful for 20 years, and many programmes depend on it.

The next donation MoU is in its final stage. We have to communicate better with our countries when we anticipate problems including delays in shipments.

- **Arielle:** With respect to GPZL, whatever consensus or new information we have, we should share before the Leadership Team meetings. Ganga and I will work with Bill to make sure that happens. There is clearly a role for Novartis and WHO. There is also a role for countries. Better understanding this dynamic of how to work with countries is a learning curve and one that we take seriously moving forward.

IV. Update from Leprosy Diagnostics Working Group: Sundeep Chaitanya

- **Sundeep:** The objective of the Leprosy Diagnostics Working Group is to foster the development of a target product profile (TPP) for a leprosy diagnostic. The working group brings together experts in laboratory science, experts in the clinical aspects of leprosy, and representatives from major stakeholder groups in the leprosy community to achieve this objective.
 - High-level milestones include TPP refinement and development, TPP review, and TPP publication.
 - Our top two priorities are:
 1. Point-of-care test to screen for subclinical infection of household and familial contacts of confirmed leprosy case
 2. Confirmatory diagnostic test for leprosy when an individual manifests early signs and symptoms of leprosy
- **Cairns:** There is significant overlap between what Sundeep presented and the prioritisation group. There needs to be coordination between those two groups.
 - **Andie:** I can coordinate that.
- **Erwin (chat):** I don't like the wording "screen for subclinical infection." Screening has the connotation that it is a first test which needs to be confirmed, thus with lots of false-positives. "Subclinical infection" looks like duplication. If there are signs and symptoms, then it is disease. Without signs and symptoms, we call it infection.

- **Sundeeep (chat):** Thank you, Erwin. We are still discussing some of these terms (screening; subclinical infection and so on). We will discuss your points further at the next meeting and will consider them in the draft TPP.
- V. Update from Country Modeling Working Group: David Blok
- **David:** The Country Modeling Working Group formed to support advocacy for new strategies and resource mobilization.
 - Objectives include: 1) assess long-term impact of SDR-PEP strategies, 2) estimate associated cost per strategy, 3) identify strategies that are resource-saving over time.
 - We focus on the 11 country partners as part of the GPZL country review. We focus on the national and subnational level.
 - Key outcome measures: 1) New leprosy child cases, 2) Any new leprosy cases, 3) Resources that would be saved
 - Proposed main scenarios: 1) Routine scenario 2) Contact-based SDR-PEP
 - Next steps: We will finalize the model predictions and cost estimations in December.
- VI. Closing remarks: Bill Simmons
- **Bill Simmons:** Please share closing comments or if you would like, circle back to Alice's comments from the beginning.
 - **Geoff:** Circling back to Alice's comment: I've been thinking about the Partnership's perception among the countries—not only the 11 partner countries—because of the new GLS. The first pillar says country-owned roadmaps in all endemic countries. GPZL focuses on 30 countries, not all countries. If GPZL isn't going to do that, then who is going to do that? We should think about this.
 - **Ganga:** Alice's feedback is very important, especially from a distribution point of view. We have been working hard on this topic, but today has given me reflection on this.
 - **Taka:** Alice mentioned an accountability mechanism. Maybe we can be more specific, like a "communications system with key stakeholders." At the country level, many people do not know about the Partnership. It's important to make sure stakeholders know who we are and what we do. Maybe we can organize in-country consultations with stakeholders. I made a presentation about the Partnership in Bangladesh for government key stakeholders. After my

presentation, they decided to put “Zero Leprosy” in the title of the national leprosy conference. In-country consultations could be useful to let people know what we are trying to do.

- **Bill Gallo:** In my short time here, I have been working to understand what is Partnership work versus the work of the partners. I look at the Partnership as work of the partners and that there shouldn't be competition for who gets credit. The main priority is that the work is relevant to achieving our mutually agreed-upon goals. However, there may be a need to amplify the work that could only be achieved by us coming together. This may require us to look at new ways to communicate our accomplishments at local and national levels.
- **Bill Simmons:** The partners are not new. They are not new to stakeholders on the ground. The thing that's new is the Partnership. It needs to matter to people on the ground.