

## Leadership Team Meeting Teleconference

6 March 2019

### Participants

#### Leadership team members

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- José Ramirez, Board Member, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Mauricio Lisboa Nobre, Technical Advisor, The Brazilian Leprosy Program, General Coordination of Leprosy and Diseases in Elimination (CGHDE)

#### Guests

- Jan van Berkel, President, International Federation of Anti-Leprosy Associations, (ILEP)

#### Secretariat

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

#### Invited but unable to attend

- Fareed Mirza, Head of Healthcare Outcomes and Research, Novartis Foundation (Chair, Research Agenda working group)
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- Alice Cruz, UN Special Rapporteur (observer)
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)

**I. Welcome from Leadership Team Chair Bill Simmons****II. Secretariat update (Courtenay Dusenbury, Jessica Cook)**

- Charter: The secretariat is working on drafting a revised charter for the Partnership. This will be distributed on 15 March and will be discussed during the upcoming meeting in Greenville on 21-22 March. The new version of the charter attempts to streamline voting and nominations for the leadership team.
- Country representatives from Sub-Saharan Africa: The secretariat proposed voting on country representatives from sub-Saharan Africa at the upcoming Greenville meeting.
- The WHO 2020 Targets Survey: The secretariat has completed the initial round of the survey and received 182 responses. It is now being sent to additional country programme managers for their feedback. An analysis of these responses will be presented toward the end of March. The secretariat feels that this analysis will be of interest for the leprosy community and for WHO.
  - Arielle asked about the next steps for this survey, asking what WHO will do with the information and whether there would be a process for them developing their own feedback.
  - Courtney replied that WHO is still working through the process they're going to use, and that we have an opportunity to help them think through the process, but that they are committed to working with us on this.
  - Geoff added that the WHO is working on targets now, and told the team that this target identification will be a prolonged process, and will probably take a year and a half to finish.
- Resource mobilization plan: Comments on the resource mobilization plan have been submitted and are being incorporated in the revised document. Courtney highlighted one of the changes in the next version: communications has been split from resource mobilization and partnership. The secretariat is proposing that a communications subgroup will form apart from the resource mobilization group to take responsibility for and focus on communications tasks. The two groups will work closely, but the resource mobilization group will focus on partnerships at country and local levels. The three objectives of the resource mobilization plan are a call to action and advocacy campaign to garner interest and investment in a zero leprosy future, aligning existing resources for the resource agenda, and investing at the country level.
  - Geoff asked why this group is called the Partnership and Mobilization Group instead of a more generalized Advocacy Group?
  - Courtenay responded that these are two different functions- there are people that are working on communications and advocacy, and there are people who are fundraisers who are bringing in money. We want to make it clear that the role of this group is to bring in resources.
  - Geoff asked about the goals of the communications group.
  - Jessica talked about the session she will be leading at the ILEP communications workshop on 19 March in Greenville. In that session she will talk about Zero Leprosy's communications strategy and goals, and she thinks that there will be good candidates for the communications group in that ILEP workshop. She added that the partnership is considering looking outside the greater leprosy community for participants in the communicators group,

- and added that she thinks it will be more operational and less focused on strategy than the other resource mobilization group.
- Courtenay expressed that she felt it would be really unwieldy to put all these people together and that she is hoping this split will allow the partnership to be more effective in operations.
  - Arielle asked if the communications group would be considered its own working group, or if it would be housed under the resource mobilization working group as a subgroup.
  - Courtenay responded that it could be considered a sub-group. The communicators in this group will take responsibility for the first goal in our resource mobilization plan and the resource mobilization group will work closely with them on this.
  - Jan asked how the resource mobilization working group plans to address in-country resources.
  - Courtenay responded that she thinks that approach could be considered as part of the goal to advocate for pre-existing resources, like from the ministry of health.
  - Jan responded that dealing with national programmes is a less common fundraising source for fundraisers like the individuals that will be joining the working group. He suggested that the strategy for approaching these sources of funds be well discussed and planned.
  - Erwin advocated for developing costed national plans, which indicate the available and committed funding from various sources and funding gaps to find out what resources are available at country level. These plans can then be the basis for approaching donors to support countries. He explained that we now we work rather in an opposite way, knowing how much funds are offered and then developing a proposal based on this. This doesn't promote much long-term strategic thinking.
  - Courtenay responded that part of the fundraising model is about bringing the resources around the plan that's developed. The partnership's model for fundraising is on the national level and is about bringing donors together. She said that point can be made more explicit in the mobilization plan document.
- Next steps for the partnership and resource mobilization working group: A call is being planned for the week of 11 March. During that meeting the secretariat and group members will discuss how the group is structured and who should serve as high-level advisors—people who are available to support the group activities and leverage relationships with key players. These advisors are being asked to fulfil this role because they have said that they're happy to make connections, but can't serve on the committee themselves because of time constraints.
  - Communications update from Jessica: The secretariat is revising GPZL's communications plan and key messages. Last year GPZL focused on building awareness and support for the partnership. This year we are expanding our goals to target countries and national programme managers, and are coming up with strategies for building advocacy around the idea that zero leprosy is achievable.
  - Arielle added that the advocacy approach is not only important for new countries, but also important for existing and new donors.
  - Emails sent in the last week by the leadership team regarding organizational strategy contained good communications ideas and Jessica will be integrating these ideas in the new plan.

- Jessica also introduced Andie Tucker, new Communications Specialist for the partnership.
- The Greenville Meeting: Strategic planning will take place in Greenville. An agenda for this meeting will be sent toward the end of next week. In the meantime, Courtenay asked the leadership team to continue thinking about their aspirations and goals for the partnership, and future opportunities.

### III. **Research Agenda Working Group (Courtenay)**

- Courtenay, David, Fareed and Arielle spoke last week and the research agenda is slated to be published in PLOS 1. It will be submitted by 28 March.
- The secretariat has finalized sub-group reports and has sent those to the facilitators for a final review. The secretariat is also working on a summary of those reports for a more general audience.
- A draft of the research agenda manuscript has been sent to facilitators for comment, and Courtenay is working with Fareed to incorporate these comments into manuscript. Looking through comments received Courtenay feels that there are significant issues, especially with the section that deals with the prioritization of research. The secretariat is convening a call of facilitators this month to discuss some of those technical issues and come to a resolution. Facilitators will then send the manuscript to groups for comment.
- Fareed said he's talked to the editors of PLOS 1 in advance and that the manuscript can be pushed to publication quickly.
- Bill asked what type of discussion will we have in Greenville related to research?
  - Courtenay responded that there will be a copy of the research agenda manuscript close to finalization that can be reviewed and discussed by leadership team at the Greenville meeting.
- Jan said the Leprosy Research Initiative (LRI) is having its spring meeting 4-5 April with about 60-70 researchers. A half day will be spent discussing the research agenda and the potential follow-up to implement its recommendations.
- Erwin added that he believes the research agenda will address the need for new tools (diagnosis, prophylaxis).

### IV. **Operational Excellence Working Group (Christine Fenenga)**

- Christine reported that there is a complete number of facilitators for the 11 groups and all groups have now met once in February. Except for a few challenges in connecting into the conference call, group communication is going well. In addition, the group is working on Google Drive to share docs and on WhatsApp groups to further facilitate communication.
- The first meetings centered around introducing members, objectives, and tasks. Discussions on framing the subthemes took place to prevent duplication between group activities and objectives. Christine added that framing and categorizing sub-topics and audience groups will also be important in the future for building the toolkit.
- All groups are working on best practices and are identifying and filling Best Practice format A (summary format). Small core-groups in each sub-group will review and screen the incoming summaries and select those that meet specific criteria before members develop format B. The first

completed formats A have come in and Christine anticipates receiving the first completed best practices in format B towards end of April.

- Important points have emerged during the group meetings:
  - The need to stress this is not a research group (especially for group members that come from academia. Some have expressed a desire to quickly move to research and scientific evidence).
  - Deeper consideration of how persons affected should be engaged. Some sub-groups have good representation of persons affected, but not all groups. Members should engage persons affected at national or regional levels to overcome language and other technical barriers. Christine will meet with the panel of persons affected at ILEP meetings in Greenville to discuss how they could be more engaged and provide input.
- The steering team meets online monthly and shares and discusses progress and experiences.
- Toolkit and Help Desk: The secretariat has developed a list of requirements for the Zero Leprosy Toolkit and Helpdesk. Next week they will be meeting with an IT developer from Infolep and Info-NTD. Key considerations in this discussion are efficiency and sustainability.
- Country reviews and road map planning: Christine reported that a draft country review tool was developed on basis of NTD Action Framework and in collaboration with WHO. It is now under review with the steering team and with Alice Cruz. An issue to be considered is the development of the visioning road maps. Which definitions and parameters for Zero Leprosy are we to include here? Further input is required from WHO's Global Leprosy Programme, who are currently working on their Strategy beyond 2020. GPZL will discuss this issue further at the Greenville meeting this month.
- The partnership has received a formal request from Nepal for a country review by the end of June. Christine is working with national leprosy programme manager Dr. Rabindra Baskota, who is serving as chairperson of sub-group 1, to coordinate this review. The Nepali Ministry of Health has committed to paying some of the costs of the review, which is a great sign of commitment and support for this process.
- Christine asked the team if they had read the concept note on the country review tool, and if they agreed with the approach. She also asked if the leadership team had suggestions of people that could review this tool.
  - Geoff reported that he'd read the concept note and sent it to ILEP's member assembly to review.
  - Arielle said she'd offer written feedback on it soon.
- International Leprosy Congress (ILC): Christine developed an abstract for the operational excellence working group. She has sent the manuscript to Christian Johnson and Paul Saunderson and is in discussion with them about it.
  - Erwin added that GLP has also requested for a mini-symposium (about one hour) primarily to give a chance to country programme managers to present success stories. Identified countries include: DRC, Nepal, Sri Lanka, Somalia and a multi-country project in Latin America about telemedicine.

**V. Updates and comments from Leadership Team members**

- No updates

**Additional items from the Secretariat:**

- Courtenay expressed that the secretariat thinks it would be useful to have an article in Leprosy Review. She would like to begin work to put this together after the strategic planning meeting in Greenville. The formal submission would come from the leadership team, with support from the secretariat.