

Leadership Team Meeting Teleconference

7 January 2019

Participants

Leadership team members and guests

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Jan van Berkel, President, International Federation of Anti-Leprosy Associations, (ILEP)
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- Alice Cruz, UN Special Rapporteur (observer)
- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- Fareed Mirza, Head of Healthcare Outcomes and Research, Novartis Foundation (Chair, Research Agenda working group)
- Takahiro Nanri, Executive Director, Sasakawa Memorial Health Foundation
- José Ramirez, Board Member, International Association for Integration, Dignity and Economic Advancement (IDEA)
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)

Secretariat

- Courtenay Dusenbury, Secretariat Director
- David Addiss, Senior Advisor
- Jessica Cook, Communications Director
- Christine Fenenga, Operational Excellence Coordinator
- Tonya Duhart, Operations Manager

Invited but unable to attend

- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Taye Letta, Leprosy Prevention and Control Manager, Ministry of Health, Ethiopia
- Mauricio Lisboa Nobre, Technical Advisor, The Brazilian Leprosy Program, General Coordination of Leprosy and Diseases in Elimination (CGHDE)

I. Welcome and Update by Leadership Team Chair Bill Simmons

Bill opens the meeting and welcomes Alice Cruz, the newest member to the leadership team.

II. 2019 Resource Mobilization and Advocacy Strategy update (Courtenay Dusenbury)

- Courtenay Dusenbury will send the strategy to the leadership team the week of 7 January. From the leadership team's discussion about barriers for zero leprosy, the strategy has four objectives:
 - Moving the political will towards zero leprosy
 - Funding research agenda priorities
 - Political, technical and financial support for country partnerships
 - Building stronger linkages in NTD arena and other organizations—to expand our influence and engage with donors

II. Communications and membership update (Jessica Cook)

- A one-page information sheet was shared with the leadership team. Other materials such as PowerPoint slides and detailed messaging documents are available on Google drive. Leadership team members are encouraged to contact Jessica with any specific communications needs.
- World Leprosy Day is 27 January. The partnership will promote the content created by ILEP on ending discrimination and stigma. In addition, the secretariat is developing a photo slideshow and possible video to highlight the progress of the partnership, the vision and the work ahead.
- The partnership has over 400 members, including members of each working group.

III. Research Agenda Working Group (David Addiss and Fared Mirza)

- An initial draft was shared with the leadership team, although two sub-group reports have not been submitted yet. Fared and David emphasized this is the first draft and the report will undergo much review and editing. They welcome comments and feedback.
- Fared and David are also working on a succinct version with graphics for a manuscript version, possibly for PLoS-NTDs. It is expected that a manuscript version will be ready for submission in the next 6-8 weeks.

Discussion:

- José observed that the term Hansen's disease is not used in the report. Also, in many countries, the disease affects women more than men, but the term "women" is never used. In the diagnostics section, "avoidance" (i.e., people who refuse to get diagnosed for fear of stigma) is not mentioned. The term "expert opinion" is used quite a bit, but it does not appear that persons affected are included. José also asked about the involvement of the U.S. National Hansen's Disease Program.
- Fared responded that he has met with the team at the U.S. National Hansen's Disease Program. They will be sent the draft report for review. In addition, he recommends that that an internal review of the report be devoted to the terminology and its use in the report.

- Bill asked for a distinction between (1) the manuscript for scientific community and (2) a public, succinct document on the research priorities, used for resource mobilization.
- A question was if the second document needed to wait until the manuscript was published. Courtenay commented that both documents (the Research Agenda or “Road Map” and the peer-reviewed publication) were deliverables in our 2018 grant. Partners, members and donors are keen to see them. The sooner we can share research priorities and gaps with potential funders and stakeholders, the better. These stakeholders want to see results.
- Cairns suggested that the plan for the research agenda extend beyond publication and Erwin asked if we could move forward with a living document that will evolve. David agreed it should be a living document that should be updated annually.
- Geoff asked if he could share with the ILEP members the research priorities. David and Fareed said a more polished version would be ready in a month, but in the meantime, suggested sharing the COR-NTD presentations.
- Geoff also asked that the language be sensitive in defining urgent priorities, and Bill agreed, but suggested we did not want to sacrifice the near-term priorities and their importance.
- José also commented about language specifically for “Operational Research,” such as house-to-house searches under case finding. The secretariat will follow up with José by email.

IV. Operational Excellence Working Group (Christine Fenenga)

- The working group includes 181 people (168 open call members, 13 steering team members) and Christine has assigned people in the 5 thematic sub-groups. She had to sub-divide these in 11 sub-groups based on interests, language and continent (max 2 continents per sub-group to ease the on-line sub-group meetings).
- They steering team will submit action plans 15 January, and the sub-group meetings will begin in February. On 17 January, the steering team (facilitators and chairs) will meet via conference call to discuss the sub-groups. Christine is in the process of finding a few additional facilitators for the French and Portuguese speaking groups.
- For communications, the steering team and sub-groups will use RingCentral facilities, What’sApp groups and Google drive for sharing documents.
- Sub-groups will begin working on content for the toolkit. A standard format and guidelines for identifying and documenting best practices is being prepared and will be shared with the steering team.
- Initial content will be uploaded to the online toolkit in April. The official launch of the toolkit will be in September at the World Leprosy Congress. Christine is also continuing to see how we can align the toolkit with InfoLep.

- Christine is currently coordinating an abstract for the International Leprosy Congress. The session may include information about the first country review.
- A briefing meeting is also being planned for the technical advisory team, to clarify its role.
- Christine will meet with WHO at the end of January to discuss the country assessment tool. Two-to-three country reviews are anticipated for 2019, working in close coordination with WHO.

V. Closing comments

- Alice Cruz congratulated the group for all the efforts, and offered several comments:
 - She suggested participation of persons affected be included in all groups, not just topics of stigma and discrimination. She also asked that the participation in groups be framed for different audiences, as it will be different to participate as an expert vs. person affected.
 - For the research agenda, she recommended including an ethical dimension in implementing research.
 - She is glad to see that the social model of disability is included and UN guidelines are acknowledged. Alice is finishing a toolkit that can be used to evaluate progress toward the guidelines and will discuss indicators during our March meeting.
 - Finally, Alice recommends that the results of the research working group be communicated to persons affected and health professionals in an accessible way.
- Jan asked about broader representation of persons affected on the leadership team. Courtenay responded that no action has been taken but that the secretariat will make it a priority this year.
- Geoff asked about the WHO post-2020 target questionnaire, and Courtenay said it was being reviewed by a few team members but a draft would be shared next week.
- José asked for a simple registration process for persons affected for working groups and asked that the partnership think about a universal definition of stigma.
- Jessica affirmed other comments about reframing our language for different audiences.
- Erwin and Cairns commented that they are happy with how all the work of the partnership was progressing.

Action Items for the Secretariat

- The resource mobilization strategy will be sent to the leadership team this week.
- The draft questionnaire for WHO post-2020 targets will be shared next week.
- A timeline for the completion of the Research Agenda and peer-reviewed publication will be developed and sent to the LT.