

## Leadership Team Meeting Teleconference

2 May 2019

### Participants

#### Leadership team members

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- Anil Kumar, Deputy Director General (Leprosy) of the Ministry of Health and Family Welfare, Government of India
- Mauricio Lisboa Nobre, Technical Advisor, The Brazilian Leprosy Programme, General Coordination of Leprosy and Diseases in Elimination (CGHDE)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Geoff Warne, CEO, 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, Operational Excellence Coordinator, Global Partnership for Zero Leprosy
- Andie Tucker, Communications Specialist, Global Partnership for Zero Leprosy

#### Invited but unable to attend

- Jan van Berkel, President, ILEP, Director, Netherlands Leprosy Relief
- Alice Cruz, UN Special Rapporteur (observer)
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- José Ramirez, President, IDEA

**I. Welcome from Leadership Team Chair Bill Simmons****II. Communications update (Jessica Cook, Andie Tucker)**

- NY Times Submission: The GPZL leadership team helped to shape an op-ed submission to the New York times last week. The op-ed was submitted but was not accepted for publication by the Times. The GPZL communications team would like to submit the existing op-ed to other publications, like the Guardian which recently ran an article about leprosy in Nepal, to seek publication elsewhere. If the op-ed does not get picked up by a major press outlet the communications team will publish it to the zeroleprosy.org website and other blogging platforms, like LinkedIn or Medium.
- Webinar: The partnership is holding a webinar on 29 May, and the secretariat will send more information about the webinar to the leadership team next week. The purpose of the webinar is to discuss the partnership's country model and open a forum for questions about the model. The audience for this webinar is primarily ILELP members because of the role they're going to play in the implementation of the partnership's country model. The partnership is anticipating we will host future webinars and will likely target the next one to National Leprosy Programme Managers.
- Toolkit website progress update: The secretariat has started work with a design team on the architecture of the toolkit, focusing on requirements and functionality. We expect that we'll have a design for the user interface soon and we'll have the toolkit structure by June. We'll be adding content throughout the summer. Our goal is to have a toolkit we can launch at the international leprosy congress in September.
- Messaging update: Jessica Cook has received edits on messaging documents and on the communications plan she sent to the leadership team for review. She's incorporating those edits and will be sending them back out next week. These are foundational documents that will help us build other documents and written pieces, like the NY Times Op-Ed.
- The secretariat communications team is also working on abstracts for conferences, like COR-NTD and NNN.

**III. Research Agenda Manuscript (Bill Simmons, Arielle Cavaliero)**

*Bill Simmons invited Arielle Cavaliero to give an update on the status of the Research Agenda.*

*Discussion:*

- Arielle Cavaliero: The question of publishing has been settled on a high profile journal, like The Lancet Infectious Diseases. Novartis has worked with them in the past, and we're working to connect with them again to understand what they're interested in, and what kind of process or timeline would be involved. As that information comes in we'll keep everyone updated.
- Bill Simmons: Is W. Cairns Smith involved in this?
- Arielle Cavaliero: Once there's a point of contact at the Lancet established we'd like to connect with W. Cairns Smith to ask for his help shepherding the process.
- Bill Simmons: I think we need to increase transparency on where we are in the process of publishing. An update once a week would be helpful. We're excited Arielle Cavaliero is helping to get us through these first steps in connecting with the Lancet.

- Arielle Cavaliero: I will soon be bringing on a colleague as maternity cover. I'll make sure she continues this work, and I'll be having her increasingly take more of a lead.
- Erwin Cooreman: Last week we had a meeting of National Leprosy Programme Managers and we introduced the contents of the research agenda and there was endorsement and buy-in from the programme managers.
- Cairns: I think that endorsement will be important to The Lancet.
- Arielle Cavaliero: We can report the process for review in the submission to The Lancet.
- Bill Simmons: Jan and I have been discussing LRI's research agenda and harmonizing with the partnership to ensure that anything LRI publishes is informed and points to the partnership's research agenda. W. Cairns Smith, I invite you to engage in that conversation. We want to further explore how these two agendas can be brought into one unified thing.

#### IV. **Operational Excellence Working Group (Christine Fenenga, Bart Vander Plaetse)**

- Progress is being made with the best practices content and reviewing of the submitted formats. The sub-thematic groups are still meeting once a month though the attendance is dropping, which is something we also observed last year with the Research Agenda Working Group. We had to terminate one of the disability groups and divide members over the other groups. Though smaller, we believe that the members still participating are highly motivated and are completing their work with dedication.
- We developed a scoring mechanism and guidelines for the reviewers to conduct the review process in a way that's structured and transparent. Review criteria were developed based on guidelines from the WHO and experiences with health system strengthening methods. We gave different weights to the criteria but tried to keep it easy to apply. One group has conducted their first reviews and indicated that the scoring was not causing any problems. After reviewing the summary best practice, we've requested authors develop this in a full format which then will be uploaded in the toolkit. We anticipate the first uploads in June/July. We received some comments from Jan van Berkel to further improve on the clarity of some of the questions. More comments are welcome.
- Bart Vander Plaetse commented that he invites the Leadership Team to give feedback on the best practice guide and scoring tool. This will lend to the credibility of these tools.
- Country reviews and roadmaps: Preparations are underway for the first country, Nepal, which will take place from 7-17 July. The second country we recommend for country review is Morocco. We have received an official request for review from both countries. Reviewing these two countries will give us experience in different contexts, with regards to continent and burden of disease, in our first pilot year of reviews. Other countries that have showed interest are India, Brazil, and Bangladesh. We will need to manage expectations with these countries as this is the first year of country reviews and we do not want to overpromise to potential review countries.
- Christine Fenenga and Andie Tucker are working on a web-based application form for countries to apply for future country reviews and roadmap planning. Christine Fenenga is working on a process document of the Country Model which will be shared with the leadership team by mail in the coming week.
- Preparations in Nepal are happening in close collaboration with the Ministry of Health and Nepal's leprosy programme, WHO (in-country and WHO/GLP) and GPZL. The review team will be composed

of reviewers from Nepal, the WHO, and GPZL, including ILEP members. We expect to receive the Terms of Reference after this weekend and will then select 3-5 candidates to be proposed to Nepal MoH. We feel that it is important to mention again that it is critical that the country review process (review, roadmap planning, choices for technical support) is owned by the country undergoing review.

- Upcoming conferences: ILC- Manilla 11-13 Sept (confirmed to organize a session 1.5 hours); NNN- Liverpool 17-19 Sept (abstract workshop session to submit before 15 May); COR NTD-meeting Baltimore 18-19 Nov (abstract to be submitted by Courtenay Dusenbury).
- A small team with members of the Operational Excellence Working Group and GPZL Secretariat will work on the preparations of these meetings.
- Bart Vander Plaetse: There was a lot of interest in the partnership at the recent Bangkok meeting, and quite a few people already knew what it was. We had people that said they'd become members. There was representation from the Nippon Foundation, Sasakawa Foundation, and National Leprosy Programme Managers.

#### V. Resource Mobilization Update (Courtenay Dusenbury)

- We are recommending that the partnership apply for the MacArthur 100 Million & Change grant. This grant is due in August. It's 100 million dollars granted over 5-7 year period. If selected we'd work over the next two years to develop the full proposal. We're suggesting that every partner in the partnership can play a role in proposal. On Friday we're going to discuss timelines and roles and responsibilities, after which we'll bring everyone to the table to talk about roles, major components of the grant, countries, and what objectives we want to achieve.
- Julie Jacobson has come on board as a senior advisor and will work with GPZL through December. She's looked at our work plan and strategy for resource mobilization, and believes we're moving right direction. Next week we're going to be working on list of key donors or partners we'll focus on this year with Julie. After next week we'll have a better idea of who we will focus on and how to reach out to them, and we will be engaging many of you in these efforts.
- COR-NTD meeting: Last year we made a presentation on the research agenda at the COR-NTD meeting. This year we think we should focus our presentation on the application of the country model. We'll send you further information about this. We're also looking at involvement at ASTMH.
- We had the opportunity to meet with Dr. Anil Kumar this week and it was great to talk about the accomplishments that have taken place in India over the past 3 years. It's an honor to work with all of you.

#### VI. Updates and comments from Leadership Team members

*Leadership Team members were invited to give closing comments and updates.*

- Bill Simmons:
  - Is there a way to formalize the programme managers' support of the GPZL country model in the Bangkok meeting?
- Erwin Cooreman:
  - The Bangkok meeting will have a report, and we can share conclusions and recommendations of meeting, but it'll just take a few months to be released.

- In this meeting there was wide enthusiasm for contact tracing and chemoprophylaxis. To get contact tracing and chemoprophylaxis in place we'll have to get a donation for the meds. I think for Africa, if the drug is available, there will be more opportunity to implement.
- I attended a meeting in Geneva where we discussed a roadmap for NTDs, and leprosy is one of those NTDs that was discussed. We're only a small section in that roadmap, so there is an opportunity for a stand-alone roadmap for leprosy, but it needs to align with the WHO NTD roadmap.
- Anil Kumar:
  - India is implementing chemoprophylaxis country-wide, but procurement is an issue because the system for procurement is challenging. India would like someone to donate the meds so it can be implemented more effectively.
  - India has our own research group at national level. I can share our research priorities.
- Benedict Quao:
  - A few additional comments from Bangkok meeting: Capacity for implementation is an issue, but early donation of rifampicin (for chemoprophylaxis) would create momentum.
- Mauricio Lisboa Nobre:
  - The Brazilian national programme is working on a new national strategy. The new strategy includes a view on how to work with the municipalities. Now they are being grouped not only on endemic level, but also on disability and contact tracing. Municipalities will develop their own leprosy strategy and learn from each other. The national programme is planning five workshops with municipalities in the coming months. By next week, the dates for the workshops will be defined and then they will be able to give an answer to when the partnership can visit the country. We will have a June meeting of national advisory team to discuss chemoprophylaxis.
- Arielle Cavaliero:
  - We're thinking about how we bring post-exposure prophylaxis (PEP) to scale. I would encourage us to use India as case study to show how we can roll it out, because there's an aspiration to do so, but a roadmap is missing. We will have toolkit information available on how to implement PEP, but a roadmap on scaling was not an apparent outcome of the LPEP programme. Is there a home for that information in the Operational Excellence working group toolkit?
  - Certification of elimination is in the WHO guidelines and it seems to be complementary to what the partnership is trying to pursue. We should look closely at certification and see how we can harmonize it with our long-term strategy.
- W. Cairns Smith:
  - I'm sympathetic to exploring donation for rifampicin. We should have a group exploring logistics of doing that.
  - The working group and research agenda should be interfacing closely to make sure they're not duplicating efforts.
- Bill Simmons: Has there been any work done on what the cost of chemoprophylaxis would be?

- Courtenay Dusenbury: This will be part of the MacArthur Foundation grant so we'll have to do costing for the grant application.
- Arielle Cavaliero: Novartis does not have data on costs of chemoprophylaxis. We do have Erasmus University medical research and cost effectiveness work from an LPEP pilot site in India, but this information is not generalizable to a global cost analysis. David Blok's modeling is on impact, not cost.
- Bart Vander Plaetse: The ILEP technical committee is looking into this under Paul Sandersan. They're submitting a path forward to quantify the issue.
- Geoff Warne:
  - I was in the NTD Strategic and Technical Advisory Group (STAG) meeting in Geneva at the beginning of week. It's good for the partnership to engage in roadmap consultations. The first phase was short and the next deadline is in July. The group hopes to then finalize targets for 2030. WHO has shifted their focus from seeing the goal of leprosy as elimination of a health problem— it's now been replaced by genuine elimination.
  - Alice Cruz is about to visit Brazil in an official capacity and she's had an official invitation from India and Ethiopia as well. She's expecting one from Nepal. She'll visit Ethiopia and Nepal next year. We're working with her on a side event for the UN Human Rights Council meeting in June.
- Christine Fenenga:
  - It is important to collaborate between the Operational Excellence and Research Agenda groups, and we hope the country roadmaps will include research in addition to operational issues.
- Anil Kumar:
  - There are districts in India that haven't had leprosy cases, and we want to certify certain subnational level districts as leprosy-free, with continued surveillance activities. We need to certify them and put a surveillance system in place. We need to develop criteria to certify countries as leprosy free.
- Erwin Cooreman:
  - WHO has generic protocols for validating elimination as a public health problem; for verifying elimination (interruption of transmission) and for certifying eradication. These are applied by several or all NTDs targeted for EPHP, elimination or eradication. Unfortunately, for leprosy no such mechanism was ever established, which is now considered as a mistake. Therefore, we are planning to convene an expert group to develop a template dossier that countries can then use when they wish to be validated/verified/certified. Happy to hear that India is also thinking on having such mechanism for use at subnational level.
  - Drug donation for rifampicin is likely to facilitate SDR and (equally importantly) promote contact tracing. It is not so much a financial issue for countries, rather there is inertia and not knowing on how to access relatively small quantities of drug especially since countries have benefitted from donation for MDT for so many years. The Global (TB) Drug Facility – though not a donor – has single rifampicin in its catalogue and is thus in a position to supply the prequalified drug. Countries that benefit from Global Fund grants for TB are actually

compelled to buy TB drugs from GDF, so if some additional money could be identified by leprosy programmes, they could immediately place an order through the TB programmes. Other ways we may explore is to go for a global bulk procurement and supply but who will then take responsibility for supply? With exception of emergency supplies, MDT is directly supplied by Sandoz to member countries on behalf of WHO. I can check with HQ how the loose clofazimine is supplied to programmes, since this appears to be done together with MDT.