

Leadership Team Meeting

December 2019

Participants

Leadership team members and guests

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Jan van Berkel, Chair, Executive Group, Leprosy Research Initiative
- VRR Pemmaraju, Technical Officer, WHO Global Leprosy Programme (observer)
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen

Secretariat

- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Jessica Cook, Communications 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
- Cassandra Holloway, Program Support Specialist, Global Partnership for Zero Leprosy

Invited but unable to attend

- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Zaahira Gani, Project Manager, Novartis Foundation
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Alice Cruz, UN Special Rapporteur (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. Action Framework: Revised version**

- Courtenay: We think we're getting close to final version of this document. The use for this doc is to make sure partners are aligned, share with donors, national programme managers and others to explain partnership, what it is doing, and what our outcomes will be. From a fundraising perspective, using a reduction in rate is more difficult to deliver a clear message about what we're trying to do, but we're going to reflect on that with Julie. We're going to try to use them to package our overall goals about 2030. We would like to suggest that we look at the framework today, again in march, and again in November to reflect on where we are on the process.
 - Erwin: The NTD Roadmap is not yet approved. These are global targets to be used by the world as a whole. Countries have to make their own targets. Global targets are an average. Some countries will not reach them, but they will contribute to them. Too many countries blindly copy global targets, but we want countries to consider the global targets and make their own targets based on their own epidemiology.
 - José: I think there needs to be more language about capacity building for persons who have experienced the disease. You can't address stigma without capacity building.
 - Courtenay: Thank you for bringing up that point. The part of our MacArthur grant proposal that has been deemed the weakest is capacity building. We can try to better mention it here in the framework.
 - Geoff: Just considering ourselves as a PEP technical entity is too simplistic.
 - Courtenay: We have four best practices, but we don't have any other. This is not to say that other technical areas are less important, but this is a major new development in leprosy that we want to focus on.
 - Jan: Have we paid enough attention to an under-capacitated local context?
 - Mark: I think this could better demonstrate the need for increased understanding of the disease, and strengthening in-country research and innovation.

III Strategic Outline 2020: perspective and overview

- Courtenay: From this strategic outline we will develop a workplan and budget with our donor organizations, and then implement beginning in January. This strategic outline builds on the work of 2019. We have the same strategic areas that we had last year. It's tied directly to the action framework, and is our implementation outline.

IV Objective 1: Research Agenda

- Courtenay: The first objective is accelerating progress on the research agenda. We're hoping the agenda will be published late 2019, early 2020 and that we will be able to have

that document in publication. We're proposing to continue some of the work we have begun this year. We have three priority areas for research and resource mobilization that we are working on. The first is diagnostics, led by ALM and Novartis, with a linkage to the WHO DTAG. This group is going to be working on a target product profile for a diagnostic test that can be incorporated into WHO's recommendation, and will be something that we can take to donors. This is also tied to the business round table, funded by Gates and others. We're trying to get this product profile developed and move it forward as a way to try to secure funding for developing a point-of-care diagnostic test. The second item is operational research to support the programmes, and there have been quite a few topics raised by the operational research working group. We hope they can work together to develop proposals for those. We worked over the past year with effect:hope and Lepra with a proposal for Canadian Grand Challenges, with a focus on active case finding and building national capacity to implement PEP and contact tracing. We foresee similar effort around some of their key research questions in the coming year. The third effort is PEP and stigma. This has been coordinated by NLR. They hosted a meeting in Amsterdam which contributed to the development of protocols and, it has been suggested, a country matrix, that would allow countries to make decisions about PEP implementation. There may be other topics, as requested. During the meeting in Amsterdam there was discussion about whether more research was needed on mass drug administration for leprosy. This is a topic that researchers are interested in working together on, coming up with a protocol, then we would work with them to try to find donors for that protocol. For our budget, we would probably not need to support any meetings for this group— they can probably be self-funding, but we do anticipate that they will need to meet together either at the LRI meeting or another venue at some point this year. The second activity we have here is partnering with LRI and carrying forward the informal network of researchers we developed in putting together the research agenda. I know that Jan has some ideas about this. Jan, will you share your thoughts in this area?

- Jan: I would like to go back to the working groups you've mentioned. PEP and stigma is not one working group. The idea would be that NLR might coordinate both, but we think that they should be separate working groups. We're happy to take the lead on PEP, but we have contacted TLMI to see if they would be interested in championing the stigma working group. We'll be talking to them next week. Stigma is a cross-cutting issue, so it's an important point of attention, and it's related to PEP, but it's much more beyond PEP, so we think it should be a separate working group. We hope this is in line with your views.
- Courtenay: Yes.
- Jan: We are very happy to do what we can as LRI, but we know we are reaching the limits of our capacity to facilitate everything that would be interesting to elaborate.

We have opened up the spring meeting and we are now facilitating some of the consortia to develop proposals for research, but we have our own process of project funding and monitoring to secure, so we have proposed to the global partnership that it might be interesting to have the secretariat hire a coordinator for the research agenda. We see there's more to be done than we can facilitate, but also because we're inspired by the projectivity of Christine's role in operational excellence. It makes a difference to have someone dedicated to coordinating and supporting the working groups. We drafted a proposed profile for such a position and sent it to Courtenay and colleagues. We're very happy to assist in finding someone, but we think if we do not create more coordination around the research agenda then we will not make the progress we want.

- Bill: Courtenay and I talked about this Jan. I'm wondering if we might consider walking before we run on this one. What I mean by that is, I'm not sure we have enough work at the outset for a high-level person, but instead, someone who would be more of a project manager/coordinator who could ensure the working groups are progressing, that they are on agenda, and who could create over the next year a lot of visibility about the activities that are happening. Then, at some point, we may discover we need to hire a more senior person to do that role, but perhaps over the next year the secretariat could find someone to be more of a research agenda coordinator/manager for the secretariat, and allow that to develop into a real body of work that might need oversight.
- Jan: I think that's interesting, and I welcome that discussion. We are convinced we need additional capacity to keep making progress. Asking researchers to spend their time developing proposals meets its limitations. This role could really make a difference.
- Bill: I suggest we look to the secretariat to refine what this might look like, but I think the idea is great. We need additional manpower and eyeballs on the issue. That's the point.
- Cairns: At the moment there is a lot of energy and drive in the research community, and I think it's a matter of time before we find, if we don't have that person at that post, that it will strangle the development. I think it is an area where the researchers have a lot of innovative ideas, and we're going to need someone to support that.
- Mark: I think we are selling short what we are trying to achieve in diagnostics in this document. Maybe we could change the language to diagnostics and healthcare interventions, or something like that. I think we will be looking, not only at diagnostics, but at anything we can do to provide the medical interventions to improve patients' lives. I'm thinking about repurposing drugs and other things we could try to align. My other comment is on the coordination of network research. I

agree with Bill, it would be a good thing to scope out what this would entail. Potentially that's something that we could help in. We may be able to find some resources for the partnership to help organize those things. It depends on if it means operational research, which is a little different than scientific research. We would be more equipped to help with scientific research.

- Jan: We are opening the LRI spring meeting in early April. At this meeting ongoing research that's funded by LRI is presented to our scientific review committee. We've decided to open the meeting to any other leprosy researchers, not funded by LRI, that might be interested in attending to network and strengthen potential coordination. We've added another 25 seats to that meeting, and you're welcome to recommend people to attend.
- Mark: That's great. Once we as a group are clear on what we want to achieve in terms of supporting that I will be happy to look in Novartis for resources we could lend to this project. By resources I mean supporting the processes around this work, or we could look at creating a little prize. I cannot commit to that right now, but those are the kind of things I would be happy to explore.

V. **Objective 2: National Programme Strengthening**

- Christine: The objectives here are directed to supporting the national programmes. The first one is to approve and agree on the action framework. We are planning to have a meeting in January to sit with partners and countries and work out a clear plan on what criteria should be used to select the countries we want to work with, and the milestones and the methods that should be used. This implementation plan will be used for the rest of the year. We anticipate working with five countries in 2020. We already have requests for country reviews and roadmaps from Madagascar, Ivory Coast, and Nigeria. They have officially applied through the ministry of health. There are some other countries, including Bangladesh, that have expressed interest, but they haven't officially requested yet. We are working with the WHO to develop a term of reference document to divide tasks and set guidelines for working in-country with the WHO. This meeting is also planned for January. We will continue to populate the toolkit. We launched it in September, but there's still a lot of work to be done. We had a meeting in September to talk about reorganizing the operational excellence working group in a better way to keep it lively and interesting for participants. I shared last week a concept note describing what that could look like. We will incorporate this concept note into the action plan for this year. We will also evaluate the uptake and usefulness of the toolkit.
 - José: On 2.6, do you provide technical assistance to any country that asks for it, or just the countries that are partnering with GPZL through a review?
 - Christine: No, that's available to any country. We have a helpdesk with the toolkit, and any country can seek assistance using the helpdesk. We are focusing on five

countries this year, but we did two countries this year, and we will need follow up there as well.

- Taka: Once the five countries are identified, aside from the national programme managers, it would be effective for there to be a focal person for the global partnership in those countries. I recognize that the coordination with various stakeholders is crucial and sometimes national programme managers do not have authority to coordinate with various people, so once the targeted countries are identified, a focal person should be identified. Next week the government of Bangladesh is going to organize a national leprosy conference on December 11th. The theme is zero leprosy by 2030. I've already introduced the global partnership to the government and it seems that they're interested in engaging in discussions with the partnership about creating a roadmap to zero leprosy. After the national conference in Bangladesh there will be some opportunities there.
- Christine: We are excited to hear about the progress in Bangladesh and about the conference. This might be a good opportunity to work with one of the Asian countries. We agree that there should be a focal person for each country. I still think it's important to focus on the national leprosy programme manager (NLPM), but we know that the NLPMs are shifted to another position in the government or leaving. In Nepal, the NLPM is leaving to study, in Morocco the NLPM is leaving for another position. This discontinuity makes the coordination harder. I think we need to identify someone in the NGO sector in each of the countries who can be a focal person.
- Erwin: We've been recommended to identify additional priority countries, having two groups: one group of priority countries based on the burden of disease, and another group of countries that are very close to elimination that have very small numbers and are likely to get to zero leprosy in the next few years.
- Christine: I'm happy with that because I feel it's interesting to work with countries that are in completely different stages. We looked at Nepal and Morocco this year and we learned a lot from both. We will bear your comment in mind during the implementation planning meeting in January.
- Jan: When we designed the global partnership we intentionally chose names like 'operational excellence' to express the ambition of the partnership. The language in this document sounds dry and not ambitious. Its content may be, but let's keep an eye on the language.
- Christine: We can look at this text again.

- Geoff: I know this is an internal document, but it may benefit from moving the in-country work to the top of the document so it will have the national programme work front and center.
- Christine: This document has been organized in this way because there are organizational tasks that need to be done, and they need to be completed at the beginning of the year. They're listed chronologically, but we can look at whether we should switch the order.
- Courtenay; We could consider taking the 2020 plan and creating an out-ward facing version of that for the website that would help people get excited about what we're planning to do.

VI. Objective 3: Resource Mobilization and advocacy

- Courtenay: We're going to refining and developing our resource mobilization strategy. The first component of this strategy is to align existing partners around the action framework, but also the country work in at least five countries in 2020, building new partner relations globally (UN, WHO, WHA, including discussion about whether it might be time for a new Bangkok declaration activity), working nationally by combining the relationship work of Mr. Sasakawa with the technical expertise of the ILEP members and the persons affected groups. We're proposing to continue a small consultancy with Julie Jacobson to work on developing new partnership with the Gates Foundation, US AID, DIFID and others. Next year we plan to advocate through meetings and workshops like ASTMH, COR-NTD, WHO global/regional meetings, EU meetings, NNN and others to be determined. We'd like to do peer-reviewed publications this year in the area of operational excellence and some of the learnings that have come from the working group. We would like to being doing economic modeling to support advocacy. This would be modeling on a global scale and modeling for specific countries where we would be working. It would be modeling on PEP and other interventions to show donors the impact of the investment, and help national level leaders get excited about investing in leprosy. We are also talking about putting together a cost-benefit of PEP and other investments in leprosy. We have a couple of examples of this now from the work funded by Novartis Foundation by NLR, Pacific Leprosy Foundation, and others. We would like to try to come together to do a better cost benefit that we could use for national advocacy and for the development of proposals. We are considering whether it is cost-effective to come up with a global business plan for leprosy elimination. Erwin has suggested that something similar has been done for TB, so we want to explore with Erasmus, which is doing a similar plan for LF, how much the development of a global costing would cost, how long it would take, and what would be the potential impact of such a plan.
 - Erwin: I am happy to hear about the business plan.
 - Bill: Having just participated in the India evaluation, one of the gaps that became clear was that even the understanding inside the health system, the understanding

of cost for implementation for interventions was low. There's nothing to use to sit down with someone in the ministry of health and say, here's the estimated cost over the next 5-10 years to reach zero leprosy, nor is there data on the economic benefit of investing in leprosy control. We need data that enables them to understand how to advocate internally for resources and to understand, if they do that, what the impact will be. This is an essential requirement if we're going to be serious about getting to zero leprosy, especially in larger endemic countries.

- Geoff: I agree. It's not just ministers of health. It's ministers of finance that may need to be convinced. The finance ministries are more likely to want to look at a cost benefit. I would like to see GPZL's role in writing grants and leading grant applications explicitly stated in objective three.
- Bill: One of the challenges is that there is strong mobilization and advocacy that happens on your trips, but capturing those funds that come through GPZL, or even ILEP networks is difficult. Part of the challenge might be to track some of the things that are mobilized in an orbital way because we're present and helping facilitate.
- Courtenay: I think the resource mobilization strategy is pretty clear about its targets, but again, we come to the question, is our job to raise resources for ILEP members, or is it to build national capacity to get to zero leprosy. Whether the resources are going to countries or partners this continues to be an interesting discussion point, our perspective is that we don't care where the resources are going, we just want to bring more funding and technical assistance to national programmes.
- Geoff: To me, whether the money flows through ILEP members, GPZL, or countries is neither here nor there. But one of the objectives of the Global Partnership is to mobilize additional resources, as well as improving the effectiveness of existing partnerships. Every time that we see a section that talks about resource mobilization, that doesn't talk about the generation of additional money, I start to get concerned. You can do lots of things with comms and advocacy that don't produce additional resources. The additional resources are hard work, but they need to be reflected in this review.
- Erwin: We should aim for countries to dedicate internal resources to reaching zero leprosy. Some countries have money to dedicate to this issue and it will be more sustainable than external funds.
- Courtenay: I agree. There are resources available that are not through traditional donors. In the western pacific we learned that the CDC has a five-year cooperative agreement with the nations that can be amended to include additional funding for priority areas. If those nations' governments decide that leprosy is a priority, additional money can be put into the system and can go directly to the countries for that work. That would be a big win. At the same time, the issue is getting the

minister of health, the finance minister, the president to say that leprosy is a priority over other issues. This is a political issue that does require significant advocacy on the global and national levels. This is an on-going challenge that is going to be discussed quite a bit in 2020.

- Jessica: Communications' role is to support the member network, advocacy, and fundraising. Some of the communications activities that you do, like building online content, creating video, highlight members, expanding photos, etc. All of those things are marketing tactics that are building a brand for the global partnership, which indirectly, is leading to resource mobilization and supporting our fundraising efforts. This document doesn't show everything that we do in communications. There's also a lot around member engagement—we're well over 500 members, and we do communicate with members frequently. There messaging that we've been working on and an overall communications strategy that aren't included in this document. I think this leadership team really value communications. All of you recognize that you are ambassadors for the partnership, and I welcome your comments or ideas about communications— what you would like to see, your thoughts on the function of communications— please send them to Andie and myself. We welcome feedback.

VII. Objective 4: Aligned, robust partnership

- Courtenay: Our one question for the leadership team at this time about this section is: we are a membership organization, so should we have an objective or activity that's focused on adding value to the members?
 - Bill: I do not think the benefit of the partnership is *for* the members, but instead, is a membership organization where we hold a common objective, and the benefit is finding common ways to reach the destination together. That itself is the benefit of the network. We're not necessarily a membership benefit organization.
 - Geoff: I wasn't sure if that's what was meant of 4.5 or not. An annual survey is one thing, but promoting the work of the members feels different from that.
 - Courtenay: A survey is intended to gather information about our activities, and to help us understand our utility to our members, and to solicit topics that others are interested in. An objective about adding value to members would be more actively trying to engage them in the work, to promote the individuals and organizations on the website, and to feel more like a membership organization vs. a partnership.
 - Jessica: It's so that members feel like they're part of the partnership, and so that they understand the value of the partnership. I've had this conversation with Courtenay and Geoff— I often feel that leaders of the ILEP organizations understand the value of the partnership, but sometimes the staff members are less engaged. This is a continuous challenge for us, making sure our members are engaged in the work we're doing.

- Taka: I agree with Bill. We are sharing a common goal. We need to be transparent and accountable to the members, and in order to be transparent, communications with the members is very important. Jessica and Andie are doing a great job.
- Courtenay: We'll talk about how we can make this a value of our work and put it into action.

VIII. Closing thoughts

- Bill: We have the opportunity to affirm one other seat on the leadership team, which is a seat reserved for the ministry of health of India. I think it would be appropriate for us to invite the joint secretary, Dr. Shukla, to the leadership team. It's not apparent that there's any imminent replacement in the senior role of national programme director, so I think it would be a good idea. She can always defer and delegate, but we want the representation from India, and it would be advisable for us to invite her to that seat. Are there any concerns or questions about that?
 - *Unanimous consent*
 - Erwin: The Indian Government will not appreciate to dictate who should be nominated for this position. We will need to address our invitation to the Indian government and clearly define the profile of the position in the LT, the more specific, the more likely that the right person will be nominated. Of course, we will need to use our informal channels to lobby for the right person.
 - Bill: I think we did that last time, right?
 - Courtenay: Yes, thanks for that guidance.
 - Christine: Jan, you also mentioned someone from Indonesia that would be a good candidate?
 - Jan: Yes, the director general of infectious diseases in Indonesia is about to retire from his position next spring. I think he's a seasoned government official that would be helpful in strengthening the leadership team. We should wait until he retires to make proceedings simpler.
- Bill: Any other open items?
 - Mark: In mid-February we have a meeting scheduled with Dr. Mwele Ntuli Malecela from WHO. We will have time with her while she's in Basel. If there are any topics that the group thinks need to be addressed during that time, please send them to me. We should use this opportunity to convey some messages that the partnership thinks would be useful.
 - Geoff: The technology conference in March is now evolving into a potential three-day conference that will focus not just on technology but also innovative approaches

to capacity development at country level, which is part of the GPZL agenda. That's still being worked on, but it's an exciting prospect. It'll be the third week of March.

- Christine: I have shared the concept note on how we'd like to proceed with the operational excellence working group. Please have a look at that, and if you have any comments, please send them to me.
- Courtenay: We will be amending the action framework and the 2020 plan, developing our budget and our work plan, and will be sharing those with the appropriate folks as soon as possible.