

Leadership Team Meeting**6 May 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)
- Jan van Berkel, Chair, Executive Group, Leprosy Research Initiative
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis Pharmaceutical
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Alice Cruz, UN Special Rapporteur (observer)
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Mathias Duck, Chair of ILEP Panel of Persons Affected by Leprosy
- David Blok, Postdoctoral Researcher, Erasmus MC (observer)
- Amar Timalina, President, IDEA Nepal
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (observer)

Secretariat

- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Christine Fenenga, Director of Country Programmes, Global Partnership for Zero Leprosy
- Andie Tucker, Project Manager, Global Partnership for Zero Leprosy

Invited but unable to attend

- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program

I. Secretariat Updates: Courtenay Dusenbury

- I want to thank everyone for your comments on the milestones. I want to share with you recommendations for how we plan to revise these in 2020. The first milestone that we would like to recommend revising the first one, on research and the research coordinator. We suggest that we step back and pull together a group that can talk about the bigger questions. Arielle, Cairns, and Jan have already discussed this in putting together the terms of reference for the research coordinator position, but some of the bigger questions, like: why aren't major donors including leprosy in their calls for proposals? And, when there are calls for proposals, why aren't leprosy proposals being accepted? An example is the NTD Support Center call for proposals. Only one of the GPZL proposals submitted was accepted. We've discussed with the NTD-SC why that's happened, and we can share that information with this group, and further this discussion. Another issue around the research agenda is that we haven't done the priority setting that's needed. The research agenda is a good catalogue of ideas, and Cairn's article is giving forward momentum, but we still haven't set priorities for research. It's going to be challenging to get behind any particular priority if we haven't come to an agreement within the organization. I think this is particularly important for some of the members of the partnership that are funding research, like LRI, Novartis, Novartis Foundation, ILEP members. We would like to put together a short-term group, based on the input of the leadership team, possibly including representatives from other disease groups to broaden our understanding. Are there any questions?
 - Cairns: In terms of prioritization of the research agenda, there's an important piece of work done by LRI that's published in Leprosy Review that attempts to use a matrix approach with stakeholders to change it from a list into prioritization. I think there is work on-going that we should refer to in this process.
 - Jan: I think we need to act. We've been waiting for the next moves, and we want research to remain an important part of the strategy field of the Global Partnership, so I'm happy to be a part of this.
 - Mark: I endorse this proposal. I think it makes a lot of sense.
- The next major area is our work to strengthen National Programme capacity. We're proposing to work on targets and our country model. We find it challenging to lay out a path forward for the zero leprosy action framework and for national programme capacity because we don't have any targets or indicators for leprosy. WHO has an effort that's being put together, with participation from many of you, to lead to targets and indicators by this November. This is going to be important for the implementation work and for donor work. It'll help us show donors what we'd like to reach, and how to do so. The country model has been tested, but we'd like to spend time strengthening it. We

- would like to have a component on monitoring and evaluation, and we'd like to make sure that all tools from the initial assessment tool to the roadmaps are all running from the same framework, which is based on targets. We are proposing to put together a group to examine the country model this year and make sure that it's as strong as it can be. We would like to consult with folks from other disease groups, like TB, Trachoma. These groups have been working long-term on national capacity building. We would like to take a look at what they've been doing, get their insights into our work, and strengthen our model. Any questions?
- Maarten: I think this is important. A lot of knowledge is available in countries, but it isn't always reflected in actions, for example: the newest strategic plan for leprosy in Kenya, which was made in 2019, was released without the inclusion of PEP planning.
 - We would like to resolve the first two issues to have a good framework for engaging with donors. We want to have a defined research agenda and a stronger country model to be able to present these to donors. We view MacArthur as a huge opportunity. As a top 100 proposal, we now have access to resources from MacArthur, including technical assistance, to help us promote our zero leprosy plan with high wealth individuals and institutions. We have reached out to some of your communications and fundraising staff to figure out how to better use these resources to the benefit of the Partnership. We view MacArthur as an engagement with everyone in the network. We'll all be able to benefit from this. We think it's important to keep reaching outward in resource mobilization. We think there are opportunities to work with TB, new funding from COVID-19 response, and looking at other disease groups and learning how they've been able to make their case with donors. Any questions?
 - Geoff: Were you meaning that some institutional donors may be hesitating to donate in the current situation?
 - Courtenay: We've seen a freeze on foundation activities in the past two months, and it seems as though large foundations, like Gates, are regrouping their resources around COVID-19 response.
 - Erwin: Regarding linking with COVID-19, in the acute phase of the epidemic there isn't much for leprosy to link with, because we are downscaling our activity. However, COVID-19 will have a lasting impact that may not go away completely, and it will alter the way services are delivered in the second phase. Leprosy will be able to be more involved in this second phase.
 - Jan: In remote areas, some of our leprosy staff are able to reach out to health centers that are not reached by national governments. This gives us an opportunity to facilitate support for persons affected. We are making ourselves

useful, to the benefit of persons affected, and are also showing that we have a relevant presence in some of the weakest parts of the health system. I wouldn't say there's no linkage between leprosy and COVID in the present phase. We are there, we are relevant, and we are able to intervene to prevent the exclusion of persons affected in measures taken.

- The NTD roadmap is one of the documents being considered on the auxiliary agenda. Our understanding is that if no country has objections with the roadmap it can be deemed as approved by the WHA.
 - Erwin: I haven't heard anything more than what you have reported, but I imagine, since it's already passed the executive board, and that board had made objection in January that have been addressed, that the roadmap will be approved.
- We are in the process of screening for our new communications specialist. As previously mentioned, we have a good group of resumes for that job. They will be screened by a panel of communicators and program folks at the Task Force. We will keep you updated on the top candidates. For my position we have received more than 11 CVs. 5 individuals were born in the US, and the rest were born elsewhere and may be working elsewhere: Brazil, India, Australia, and a few other countries. Two work at the US CDC. Most of them are working in other disease groups, or for foundations, or are managing large donor driven projects, some in the 75-million-dollar range. We feel there is a good group of candidates. Our process is that there will be a phone screening of initial candidates, a selection of a smaller group. Those resumes will be passed on to you all for feedback, and we will have a panel interview of the top candidates, and a leadership team work group panel interview of the top two candidates. I am on the internal work group to select this candidate, so I'll have the opportunity to look at all of them and talk with them. From our perspective, we're moving into a new organization phase where we're focusing on country implementation and developing partnership around research and funding. We're looking for someone that can lead program implementation and partnership effectively.
- We want to ask if having meetings every other week is preferable, and have the second meeting be a focus on what's happening with partners, our working groups, and to talk about how we can be working together. Does anyone have thoughts on that approach?
 - Erwin: The meetings every two weeks are practical now, but once we return to normal travel and work there will be outside meetings and country travel, so it may not be feasible to continue the meeting frequency.
 - Arielle: I want to echo what Erwin is saying about feasibility once people are able to start moving, but in light of the changes that are taking place in respect to the

milestones, COVID, and the short-term working groups it could be a benefit to the leadership team to continue the bi-monthly calls in the short term.

- Is anyone opposed?
 - *No opposition.*
- We'll plan to move forward with the bi-monthly meeting structure for the time being.

II. **Country Selection: Christine Fenenga and Andie Tucker**

- Thank you for giving us the time for this short presentation on the selection of countries. This is work we have been undertaking the first few months of this year. At the beginning of the year we could not predict that the COVID-19 pandemic would have such a great impact on our work, and even at this moment we don't know when we will be able to resume in-country work. Maybe we'll be able to work with some countries remotely, but regardless, we want to present to you our proposal for country selection. Last year we worked in two countries: Morocco and Nepal. At the same time, we've been trying to raise awareness about the Partnership and about the country model. We conducted a webinar on the country model, we presented the country model at different conferences to garner attention, and the WHO has been helping us with informing National Leprosy Programme Managers. We invited countries to apply via their ministry, through the website, with a deadline of the 1st of March. In January we organized a workshop for stakeholders in Amsterdam. Many of you participated, and it helped us better define our relationships with countries and determine our criteria for selecting countries. Based on that information we created a checklist. All countries that applied to work with the Partnership in 2020 were screened using the checklist. We spoke on the phone with National Leprosy Programme Managers of applicant countries and used the checklist to compile information into an excel sheet that you received. We conducted our analysis of these different criteria, and we are now proposing our country selection. After we selected our proposed partner countries for 2020, we reached back out to some applicant countries to ask about the impact of COVID-19 on their country and leprosy programme. Many countries responded that their work had been shaped by the crisis and that they were unsure when they'd be available to work with the Partnership, or conduct a review of their programme. There is a great deal of uncertainty right now about when programmes will return to normal. 23 countries have shown interest in working with us, and Papua New Guinea has applied to work with us since the deadline. Many countries from Africa applied. India, Brazil, Indonesia, and Bangladesh are high burden countries that are considered priorities and the leadership team has decided that there should be some kind of support from the Partnership to those countries, irrespective of the country selection. We didn't get an official request of support from any of these high burden countries. When looking at the criteria, there are four areas of consideration: country engagement and commitment, programme

management and needs (surveillance, data quality, human resources and training, innovations), epidemiological data, situational factors (political cycle, planning cycle, security, stability). For most countries we only spoke with the National Leprosy Programme Managers, but in some cases, there were also NGO representatives present on the phone calls. If you spoke with all stakeholders you would get more information, but for the most part, we only spoke with NLPs. There were a few late applicants that we corresponded with via email, instead of telephone. A few key observations from these data: most of the applicants were from Africa, NLPs that applied represented diverse stages of development and had differences in needs. This underscored the need to contextualize the country model based on context. There was a diversity of burden of disease between the countries. We saw potential for cross-fertilization between countries. You could see some of the countries were almost in the same stage, or were maybe just a step or two ahead of another country, which would lend itself to peer-to-peer learning. Many of the countries we spoke with will need to update their strategic plan this year or next year, in alignment with the WHO planning cycle. This makes the support of the Partnership currently relevant and potentially very timely. A few countries have security problems, and the total number of countries that applied exceeds the capacity of the Partnership to support them all at once. We initially said that we'd like to try to work with 5 countries a year, but after looking at the different needs expressed by each country, we decided it may be preferable to open it up to more countries per year, depending on needs. In 2019 we learned that country work can take longer than anticipated, so that could be helped by initiating country work sooner than later. We also looked at which countries could work with each other. The differences in need across countries led us to create different support packages. We designed four packages, the first with very little support, the fourth with the highest level of support. With this information we made a Gantt chart demonstrating how countries could be supported over time. We also examined how this country selection could further our organizational goals. One minimum requirement is that the countries must be working toward zero leprosy and be willing to develop a roadmap and action plan, and to take actions toward reaching their goals. We are taking measures to link all of this work to our organizational action framework and indicators of success, with the creation of a monitoring plan. In January's workshop we discussed our desire to select countries from a diversity of continents, a diversity of burden of disease, a diversity of need, countries that would easily facilitate cross-country learning, countries that can absorb the assistance of the Partnership, and countries that can be a 'quick win', that can demonstrate the success of some of these tools and innovations. If we are going to work in more than 5 countries, we need more hands to help support this work. If we try to get buy-in from partners, and to take a leading role alongside NLPs, we can work in more countries at the same time. We also need to standardize our tools and protocols so

- other originations are aware of the country model and understand what we are trying to achieve. We have a TA pool, but we are working with the WHO and ILEP on a joint TA pool. That doesn't mean that every expert will be asked to participate every time we conduct a country review, but it'll give us a good bench of folks to pull from. Standardizing tools and protocols will also allow us to better train our TAs. We plan to conduct online training of TAs on our GPZL tools prior to a team initiating a country review. The countries we're recommending for selection were chosen based on the aforementioned criteria. We've included Nepal on the list because our work there will continue into 2020. We have the pacific islands group, then Mozambique, Tanzania, Uganda, Ghana, Ivory Coast and Nigeria. Tanzania has already started SDR-PEP, and Mozambique and Nigeria are working to start it. Uganda, Ghana, and Ivory Coast have also indicated that they would like to start working on SDR-PEP. Ivory Coast is a little more complex because it's French speaking, but we think it's important that we have representation from West Africa. We need buy-in from a lot of organizations to conduct this work, so we've named potential key partners for our work in these proposed countries. Courtenay has already mentioned this, but we'd like to set up a working group to examine the country model and establish a monitoring and evaluation plan. We want to develop targets and indicators for the action framework, and this should be tied into the WHO's task force on definitions and indicators for incidence of leprosy. We want to standardize our tools and templates, set up a TA pool, and we want to do preparatory work after countries are selected. We would like to consider which countries we may be able to initiate remote work with, in the interim time before normal activities can resume. For example, context analysis and stakeholder mapping. We may start working with Tanzania soon. We'd also like to work with NLPMs in the interim. There are many that have expressed interest in starting SDR-PEP, so we are developing training webinars with experts from NLR and the WHO. The first webinar will be mid-June for NLPMs. We are continuing to consider how we can make progress in driving forward research by assisting the research groups. Are there any questions?
- Taka: Are you communicating with WHO country offices? In my experiences with working with governments, getting support from WHO countries offices is very important. I think the selection of the first group that we've selected to support is very crucial, because other governments are watching and evaluating the work of the Partnership. It may be important to choose countries that are relatively easy to work with, and that we are confident will have good outcomes.
 - We want to work with WHO country offices. We have not included them in the process of selecting the countries. We have been in contact with WHO global, but at this stage we haven't gone to the country offices yet. But we will do so as soon as we initiate work with countries. Regarding your comment, this was one of our criteria: looking for quick wins that will build momentum and make other counties enthusiastic. On our list we

- have a number of countries that have fewer needs and have already developed plans or innovations that we can build on. It's a mixture of countries, but there are some that we expect to be more immediately successful.
- Erwin: I see that there is no country from SEARO that's included in the selected list. Cambodia and Vietnam are not SEARO, they are in the Western Pacific region. I thought that Bangladesh was very interested and I'm surprised they did not apply. We can help you in getting their application. In my opinion that could be a successful case, because there is commitment from the government.
 - We had hoped that Bangladesh would apply, but we never received anything. We also had contact with Sri Lanka, but their request didn't come through either. We will keep an eye on those countries.
 - Jan: I am puzzled about the status of India. Can you illuminate?
 - There are a number of countries that have been labeled long-term priorities by the leadership team, including India. India has had a GPZL-adjacent review, but they haven't applied officially. We've decided to look at specific need request that come from the ministry to GPZL in India, and that process started before COVID, but we need to resume it.
 - Geoff: It's encouraging to me that we're going beyond the original idea of 5 countries, and I think the idea of the support levels has been a crucial decision. I want to stress the importance of the national partnerships for zero leprosy. This is going to be one of the crucial issues for sustainability. Establishment of a national partnership with all the stakeholders in a country is an essential building block to success. My view is that in a country where there is an ILEP coordinator, the ILEP coordinator is the obvious person to be that liaison because the coordinator is elected by the other ILEP partners in country. It probably won't work well if a different ILEP member is chosen for this purpose, but we can talk about that later.
 - The working group that's going to work on the country model may also bring up new ideas about inclusion of partners.
 - Maarten: Fresh, outside perspectives can be useful when conducting country reviews, rather than only the usual suspects undertaking that activity. We should not lose momentum now, we should make use of our partners to carry this work forward. Are the tools sufficiently developed for that to be possible? Do we have a full systematic approach?
 - We do have some useful tools, but they could be revised, and we need some additional tools.

- If everyone agrees with the recommended countries, we can respond to them. If you think we need changes, please let us know.
 - Arielle: What are our immediate next steps? When would you like to communicate with these countries?
- We would like to reach out to the countries to inform them about who has been selected, and who will be considered again the following year. We also would like to get their input on when they think they'll be able to resume normal activities, and what we can do remotely during the interim.

III. Working Group Updates

Working Group 1:

- Benedict: We had our second meeting yesterday, and we've been able to resolve issues from our first meeting. We have agreed on our terms of reference. It's undergoing final review. We see ourselves more as a emergency operations center that's responding to needs of NLPMs during this pandemic, and we'll be leveraging our partnerships to help countries. We discussed the first results of our survey. 20 countries have responded so far, and we are beginning to see what is going on. Largely, core leprosy services have not been disrupted, except in a few countries. We're working to link those countries with the necessary stakeholder to address the issues. At this stage we are defining how we will respond. We are identifying stakeholders who will deal with different needs identified by the survey. We will continue to coordinate and ensure that NLPMs are on track.
- Arielle: One of the questions that have been asking is, what is our role as committee to address these needs? We know this is a short-term working group. We have a diverse team of experts that make up this committee, and we want to leverage those experts to desegregate information we're getting from countries by topic, and have them review survey responses. We're going to need to help the committee understand what response we can offer. How can we be responsive and also responsible with our promises about what we can do? There is an opportunity to put out a second survey to target the NGO community, and we'll have to decide how to marry the information coming from these two surveys. We're asking the question, when we gather this information it can change, because we're in a rapidly changing situation, so if it changes, how can NLPMs update us?
- Christine: The supply chain at the moment doesn't seem to be a big problem, and most facilities are still receiving their drug supply, but for patients are experiencing access challenges because of travel restrictions. There are many challenges related to drug access at the community level. Jan, you mentioned that ILEP partners are getting to areas that NLPMs are having a hard time reaching, so I hope the NGO/CSO survey we're sending out next will provide a lot of additional useful information on this topic. Some of

the issues we're seeing have been underlying for a long time and are surfacing because of the current crisis.

Working Group 2

- Amar: I thank my working group members for their hard work. In the beginning of this group José was leading this team, but I've filled his role at his request. Our group is seeking to create collaborative networks of persons affected organizations to gather and disseminate information through meetings, to discuss needs of persons affected during the pandemic. We had meetings with our friends in South America, Africa, Asia, and the Pacific regions. We will have further meetings with the Asia and Pacific regions. We will have an extensive report soon, but for now we will report that persons affected need basic necessities, like food, clean water, soap, etc. These needs are urgent as many are under complete lockdown. Some also require wound care. We are planning to make a video about persons affected to raise awareness and are creating a questionnaire on social protection for persons affected, to help them access available state benefits, if present. Alice is writing a statement to the permanent missions to the UN drawing attention to the needs of persons affected during this pandemic.
- Alice: We have a lot of plans ahead of us, and we will provide you with more detailed information in the future, since this meeting was mainly to discuss other issues. I'd like to highlight here that we have a concern about the impact of the information we are gathering, with regards to improving people's lives. I appreciate Jan's comment that ILEP members are reaching to people where the state is not. Yesterday, during a conversation with TLMI, we saw the importance to giving visibility to the impacts COVID-19 is having on leprosy funding. That issue will also be addressed in my letter to the member states. I would like to highlight to you that many persons affected have asked us: "What are these international agencies doing? Because we do not see impact on the ground." People don't have food, shelter, and there are many other issues. This is an opportunity for us to think together about how we can increase our impact. How can I as special rapporteur be more impactful? We need to find ways to answer these questions.

IV. Updates and Observations from Leadership Team Members

- *No observations shared this call.*