

Leadership Team Meeting

February 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
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis Pharmaceutical
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen

Secretariat

- 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

- Alice Cruz, UN Special Rapporteur (observer)
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- VRR Pemmaraju, Technical Officer, WHO Global Leprosy Programme (observer)

I. **Welcome and update from Leadership Team Chair: Bill Simmons**

- Many of you on this call were present for the dissemination report meeting, and the engagement from the Ministry of Health was strong, and the opportunity for the Partnership to serve as a mechanism to connect with the ministry was presented. I think in the short run we can engage by bringing partners together with the Ministry around the digital health platforms India is developing, and the ability to develop the leprosy component of that platform. There's an opportunity to shape the reporting around leprosy for years to come, if we are able to engage with that. We will see if we can make that happen with partners in the country. Representatives from Novartis, ILEP, the Ministry of Health, the WHO Global Leprosy Program were present and it was a good meeting.
 - Arielle: Are there any next steps?
 - Bill: The next step is for us to initiate a discussion from the Partnership to the Ministry to discover how we might set up an official collaboration in the digital health space, and how we can bring organizations together in-country around that issue.

II. **Communications Analytics Report: Andie Tucker**

- I will first share a few points from the overall communications report you have in front of you. In 2019 we saw growth across all platforms: our newsletter list is at 1000 subscribers, we saw growth on our social media channels, growth in website visitors, and we saw a large proportion of new visitors to our website in 2019. The toolkit homepage was the second most frequented page on the website in 2019. We saw major bumps in traffic associated with major events, with the ILC leading to a bigger bump in website traffic for us in 2019 than any other event that year, and we saw huge growth in newsletter sign-ups and social media follows during the ILC as well. This growth indicates that in-person engagement with our audience can be a key factor in audience growth. This 2019 report is helping us evaluate which of the tools from the tool kit are most utilized, and we'll use that to guide our translation decisions this year. We are planning to translate the top five most used tools into both French and Portuguese.
- I'd also light to highlight a few things from World Leprosy Day and World NTD Day this past week and a half. We saw our biggest-ever jump in online engagement, and that was attributable to the groundwork we laid in the months prior, and our engagement with our audience during the week. Prior to its announcement in November, we were working behind the scenes with GHS, the communications firm hired to spearhead World NTD Day, to move the awareness day because of its proximity to World Leprosy Day. When it became clear that date was not going to be moved, we began working with GHS to make Leprosy a key part World NTD Day. There were theme days every day

in the week leading up to the event. We recommended one of these themes, ‘stigma and discrimination,’ and helped to draft messages about the critical importance of addressing stigma and discrimination for all NTDs. The result of this work was that groups that haven’t engaged with leprosy frequently were exposed to messages about leprosy, and some of them shared these messages publicly, notably, ASTMH and the Gates Foundation. Another factor that contributed to the success of this week was our content and our strategy. We used content tailored to the platforms we were using: captioned videos perform well on Facebook, images on Twitter; and engaged with our audience throughout the week. Another key part of this success was using small funds to promote content to increase our reach. As a result, we saw our largest short-term growth on both platforms, with massive increases in reach, engagement, and followership— a 160% increase in the last week in a half in followers. Of all of the outcomes of the last two weeks: audience growth, growth in reach and engagements; I think our work with other NTD groups to increase visibility and credibility was the most impactful. The result of this work was greater communications alignment with other NTD groups and global health influencers, which puts us in a strong position to look forward to Kigali as a strong voice for leprosy during a key year for international advocacy.

- Bill: What was the most significant change highlighted in this report that relates to the audience the partnership is trying to reach?
- Andie: In looking at what will be happening around NTDs this year with Kigali, with the World Health Assembly, I’m concerned with making sure leprosy is well represented, and that it is well advocated so it doesn’t get lost in the NTD noise. I think we made headway on that front in these last few weeks. With the groundwork that we laid in the lead-up to World NTD Day, we were able to get messages to people that we have not been giving messages to in the past. I think that we have new potential collaborative partners within the NTD world that we can work with on major NTD announcements this year. Some of the partnership has been laid across NTDs, instead of just within leprosy, that we will be able to capitalize on this year to promote our voice. That sets the stage for us to be more successful in the future.
- Erwin: What will be the future of the World Leprosy Day? It’s very close to World NTD Day? Will leprosy day continue? In India, leprosy day coincides with World NTD Day. This year I didn’t see World NTD Day events happening in India, but the World Leprosy Day event was attended by the Minister. I don’t think India is interested in giving up on their World Leprosy Day.
- Andie: When we approached GHS we made the point that it didn’t make sense to schedule World NTD Day on World Leprosy Day in India. It seemed poorly

timed, considering the importance of India in NTD discussions. This decision was being funded by the Crown Prince Court, so it was coming from outside the leprosy world, and GHS had never done NTD work prior to this launch. When they came to us the date had, for all intents and purposes, already been set. We made the strongest arguments that we could to change the date, and we connected them with our ILEP colleagues in India to try to help them understand the gravity of World Leprosy Day in that country, but this decision was already made before we started talking about it. Our response was to stay involved, keep a seat at the table, and help shape World NTD Day planning and decision making, to ensure leprosy was not left out.

- Arielle: Were the discussions you had about NTD Day 2020, or were they about NTD Day more generally? How stuck are we on this day?
- Andie: When they came to us they'd already selected January 30th because it was the signing of the London declaration, and there was strong reasoning for it. We went so far as to present alternative days, and talk through other options. We exhausted all opportunities we had to change this, but unfortunately, it wasn't possible. They are moving forward now with making it an annual event. It seems as though Jan 30th will continue to be World NTD Day, but I think that we have an opportunity to continue being a vocal part of steering World NTD Day.

III Country Capacity-building Update: Christine Fenenga

- We are currently translating all of the input from the Amsterdam workshop into relevant documents, which we will validate and use to inform our operational support in the countries this year. I am currently in Atlanta and am working with my colleagues on creating clear documents and processes. We have been developing our GPZL Country Engagement Strategy, which is built from the steps we identified together at the Amsterdam workshop. This is a clear document that will inform external communication and help countries know what they can expect when they engage with GPZL. Linked to this document is a document that describes what we've learned from our work in Nepal and Morocco. We have developed Terms of Reference for roles like: the GPZL Focal Person, National Working Groups, the International Advisory Group; to make clear the roles of these different people and groups. We have developed a Country Selection Checklist which we can use to select countries, and we have a rough planning outline of the work we're going to undertake with five countries this year and how we're going to divide the tasks at the secretariat. We have also defined the activities for the Operational Excellence Working Group— identifying ways that OpEx group members can stay engaged in the coming years. We are also drafting an outline for collaboration with the WHO and with countries. This will need to be tailored to each country, but we are working out what we need the outline to include. You will see these documents in a few

weeks because we'd like your input. We are going to test the country selection checklist this week in two countries: Ghana and Uganda. We are going to improve it and then share it with you. We have received more expressions of interest from countries, including Mozambique, Uganda, and possibly Ghana. We have a lot of expressions of interest from Africa, so Andie is working on an advocacy package for the WHO to try to solicit more applications from other countries. Our deadline is 1 March because we want to decide soon and inform the countries that will be included. Andie and I will go through the Country Selection Checklist with each country that's already applied, and after 1 March countries will be notified that they have been selected for this year or are being placed on the waiting list. For 2021 countries will be asked to submit an Expression of Interest before November 2020 to allow us to prepare before 2021. We're starting later this year, but next year we would like to start selecting countries and preparing for country work in January. We would like to engage five new countries each year for the next 5 years, resulting in 30 Roadmaps by the end of 2025. That will give selected countries between 5-10 years to work on implementation of their Action Plan. We've learned in Nepal that sometimes this work will take longer than anticipated.

- We have heard from Nepal that the final report has been signed by the Ministry of Health. I've been in contact with Dr. Bibek and we will soon talk about next steps. We are working to establish connections with Bangladesh. Taka helped facilitate this. He has asked the Ministry of Health to hold a stakeholder meeting to discuss the zero leprosy ambitions of the country and talk about how that can be achieved. We are still waiting for a response from them.
- I'd like to update you on the COR-NTD research call. I've been asked to help coordinate the call from the leprosy community. The deadline is at the end of this week. I've been working with Nienke from LRI to offer support to the applying groups. We have nine proposals. There are three themes in the call, and the nine current proposals are representative of all the themes. My impression is that some of these groups that have applied have had a hard time shaping their proposal around the time frame, one year. These are ambitious plans and we have tried to give guidance to shorten them. We have asked everyone to include collaboration with the Global Partnership in their submission.
 - Bill: On the COR-NTD proposals, what's the general variety of geographical areas that are being proposed?
 - Christine: Most of the proposals are multi-country, but there is a focus on the African countries, especially looking at stigma. I'm not sure if there is much representation in Brazil.
 - Bill: In the next week or two we'll get the outcome of the work you're doing on country planning, and by 1 March we'll have the list of countries that have submitted for reviews, right?

- Christine: Yes, we have indicated that they can apply through the secretariat or the website, but it's the Ministry of Health that has to reply. In some cases, we have had NGOs apply, but we have told those groups to reach out to their Ministry.

IV **Government Consultancy Update: Courtenay Dusenbury**

- We sent out the budget two weeks ago, and some additional information this week. I'm planning to go through the budget briefly this morning, but before that I want to provide an update on governance. We met with a potential consultant last week, and we talked about the issues we're facing as a partnership. One is that we have additional money coming in, and we would like to create a better process for determining how we take the activities agreed to in the workplan and budget those out, and the specific process for setting priority. The second issue that may be coming is the challenge of determining where to apply for additional donor funding. Who should work together on proposals, and how do we know if an opportunity is within our agreed upon scope of work or not? The secretariat is going to need good governance on this issue, or we may face challenges in competing with other members of the partnership for funding in the absence of a transparent process. Dave Ross, CEO of the Task Force is interested in potentially conducting an evaluation of the Partnership. We've just concluded our second year, and Dave feels there are a lot of lessons that could be learned by other groups from our work, and he suggested that this governance consultant could also conduct an independent evaluation. Leadership team, is it okay for us to move forward with a discussion about fundraising and resource allocation, and what are your thoughts about an independent evaluation of the Partnership? Would you be willing to help us define the scope for that? Both of these activities would be funded by the Task Force.
 - Geoff: ILEP welcomes the availability of this resource. It's valuable. I understand the importance of defining governance. We are happy to participate in shaping the terms of reference. One thing that I think is particularly important is that the design of the governance of an organization evolves over time. We should look at the governance and make sure that the model we use going forward is appropriate, as we leave the formation stage of this organization.
 - Mark: The two proposals make sense to me, and it's important for us to think about how we allocate funds. I'm in support.
 - Jan: I support both options. One question for me is, should we have more coordination between donors? I think we should stay away from the risk of each donor choosing their own priorities and leaving essential parts of the work unfunded. I agree with Geoff's suggestion. With the leadership team only meeting an hour a month there may be benefits from having a smaller team more closely involved. The more complex our activities are becoming, the more

stress that places on our hourly meeting once a month. I don't see the need for an extensive evaluation exercise after two years, maybe we shouldn't overload it. That's a concern.

- Arielle: What would be the outcomes of this evaluation?
- Courtenay: For the Task Force, the leprosy partnership has really become a model. Other organizations are basing some of their work off our model. It could be very important to take a look at what has made the partners stick together, and the factors that have brought the partnership to a ten-year long-term commitment. There's a feeling that it is time to look at what we're doing, especially with governance, to anticipate the needs of our future growth, and put into place a governance structure that will help us continue our good work. The specific outcomes would be identified during the development of the evaluation. We're happy to have your help with that.
- Erwin: I welcome the idea of an evaluation of the partnership because it can generate momentum and provide a boost for what you're doing. External evaluations should look at impacts that have been achieved, and the impact is much broader than the partnership. Have we made a difference in leprosy control? It may be early to see that effect. It may not show the impact we have on the global level that this point.
- Courtenay: That's a good point. There was thought about the former leprosy partnership and looking at the differences between that and this partnership. This could help us identify the right time to conduct another evaluation on health outcomes in countries.
- Bill: I'm hearing we're all in support. I think this is a good process that will give us helpful clarity from an outside source.

V. Budget Presentation: Courtenay Dusenbury

- We've sent out the budget documents to everyone. It's challenging to read across potentially four donors, and I wanted to explain why we have this current budget. When we started with funds from the Novartis Foundation we negotiated directly with them, and with ILEP on specific budget lines. This was due to donor preferences or rules, which necessitated some things being in Novartis' budget, and some things being in ILEP's budget. With the additional Sasakawa funds this year we were able to work across three donors to allocate priority activities of the workplan across them. We have a desire as the secretariat to have activity-based budgeting so we can look at a meeting, or a site visit, and be able to tell exactly what was spent. This helps us with fundraising activities. We can tell donors how much it costs to implement the country model. We've tried to divide activities to specific donors.

- Bill: I invite questions around the budget that's presented and its support of the action framework and the partnership priorities.
- Geoff: Budgets are a big piece of work, and I appreciate what's been done here. I noticed that some people are classified as independent consultants even though they're part of the secretariat. It looks like there are changes in job roles. I've noticed there's a difference in Andie's role from what it has been.
- Courtenay: Yes, Christine is listed as a consultant because she's paid directly by ILEP. This allows us to avoid the indirect costs and unnecessary complication that would ensue if she were paid by the Task Force. We have previously discussed with the leadership team that this year we're moving Andie to a project management role, which is her background. She'll be working with Christine on the management of the country projects. We will be hiring a communications specialist to replace Andie. We're hoping to do this in time for the leadership team meeting in March. We have Cassandra listed in the budget, but she's received a promotion, so she won't be working on the grants anymore. We've identified someone to replace her and we're in the process of onboarding that person.
- Jan: Have you been in touch with the PEP++ team here? They worked with David Blok on modeling costs for PEP. When doing this he worked with other colleagues at NLR and at the university to develop this costing package. His work this year may require other input, and we welcome you to learn from the team at NLR.
- Courtenay: We're discussed this with Julie Jacobson. She introduced us to the International Modeling Consortium, based in London. We'd hope to work with them in the future as a second validation for some of this modelling. We appreciate your suggestion, Jan.
- Jan: I want to express my happiness that we're moving toward finding the funding needed for a research coordinator. I've committed to assist in finding the additional funds. Such a person could give a boost to the consortia that are forming around the main research priorities.
- Bill: I don't think the current governance we have a mandate to approve the budget, but I think we can say that the leadership affirms and supports the budget. The research person hasn't yet been fully funded, so anyone that wants to assist in that matter I would encourage to do so, to ensure the role is fully funded for a year.
- Courtenay: I want to thank everyone for the hard work they've put into this.

VI. Updates and Observations from Leadership Team Members

- Bill: does anyone have something to add or contribute?
 - Cairns: I think the research position is extremely important. Current technology is insufficient to reach zero leprosy, and we need to have research driven innovation. We've received a response from Lancet on the Research Agenda we submitted. They want revision and we'll do that by the end of the month.
 - Jan: LRI is preparing its spring meeting 3-4 April in Holland. We've opened the meeting to researchers that are involved in leprosy research, but aren't currently funded by LRI. This will support networking among leprosy related researchers. If you have anyone in your network that's interested in attending, they are welcome to come.
 - Mauricio: I'm glad to know that tools from the toolkit will be translated into Portuguese. I know a challenge for the Global Partnership is to increase funding from larger donors, and to attract new funders from outside of leprosy. I agree with the measures proposed by Courtenay about governance. I am happy to see that the largest increase in the budget was for country activities and implementation.
 - Bill: I will update you on the status of the leprosy vaccine and trial in Brazil. The Infectious Disease and Research Institute in Seattle is going to continue, but the process they're in will cancel their debts, and they will continue as a clinical trial organization. They've shut down many programs, including leprosy development. They maintain their ability to manage something like leprosy trials. The vaccine will continue and is still on schedule in Brazil. It's received its ethical clearances in Brazil, and Fiocruz has the personnel in place for the trial. We're optimistic that this setback won't prevent the progression of the trial.
 - Courtenay: We have a few other topics we're working on: the resource mobilization strategy, and the WHO DETAG group for leprosy. We're going to be sending around information and requests for guidance on these topics on Monday.
 - Bill: In March, we have our meeting on Monday the 16th in London, so we will cancel the call that was scheduled for 4 March. We hope to see you all in London.