

## Leadership Team Meeting

1 July 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
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (guest)
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis Pharmaceutical
- Mark Alexander Rogers, Senior Global Program Head Neglected Tropical Diseases, Novartis (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana

#### Secretariat

- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Andie Tucker, Project Manager, Global Partnership for Zero Leprosy
- Caroline Cassard, Communications Specialist, Global Partnership for Zero Leprosy
- Arielle Nelson, Communications Intern, Global Partnership for Zero Leprosy

#### Invited but unable to attend

- Rekha Shukla, Joint Secretary, Ministry of Health and Family Welfare, India
- Alice Cruz, UN Special Rapporteur (observer)
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)

## I. **Welcome and update: Bill Simmons**

- I want to provide a reflection on what it means to be the Global Partnership for Zero Leprosy. The genesis of the Partnership was a coming together of disparate groups of common purpose; zero disease, zero disability, elimination of discrimination. But that's not all that brought us together. In some ways those dreams have been shared by many for generations. We knew that by working together we were more powerful in our shared pursuit. I want to remind us today as we embark on two critical discussions that the work of this Partnership is the work of the partners. The Secretariat is not 'the Partnership.' The Secretariat helps to keep partners linked together. It helps to ensure we have a clear map for that work, but we are the force pulling the work forward. I know I've praised the work of the working group of MDT and the working group of Persons Affected, and Amar, Jose, Matias, and Alice's work in their working group. They have created a channel for many voices to be heard and amplified during this time of COVID-19. We can't succeed without the clear voice of persons affected. I want to highlight why I think the MDT group paints a picture of what the GPZL should be about. This working group has achieved alignment of disparate resources in a way that hasn't previously been done, all because they linked arms at the Partnership. That is our work, it's your work, and you did it. But it won't be enough. We know that a perfect supply of MDT wouldn't enable us by itself to reach zero leprosy, but we have come together to break the stagnation. We could lament the fact that the research agenda and parts of governance that have been stuck are stuck, or we could move forward today. The Secretariat is a vehicle of the partnership. It's up to us, the partners, to do the work. We must find the resources and bring the partnership to the front. Achieving zero as we begin the next leg of the journey calls for us to invite each other into participation. We need to renew our investment of time, energy and resources. We need to think of others first, putting the needs of the Partnership above the needs of the individual. Your presence on the call is a sign of your investment and willingness to work. I call on us to invest in this discussion, to participate in these groups and groups that will be formed, and to think of the Partnership first in your work. Getting unstuck has to start with us.
- Update on hiring process for the new Secretariat director: An offer has been extended and accepted, but it's pending some final details. We hope to be able to announce that very soon. The hiring committee is excited about the candidate who has accepted.

## II. **Secretariat updates: Courtenay Dusenbury**

- We are going to start with quick updates and move to a discussion on research priorities and governance. We are happy to welcome Caroline Cassard as our new communications specialist. Caroline is a graduate of Emerson College. Most recently she was serving in the Peace Corps in Indonesia as a secondary education English language teacher and teacher trainer. We welcome her to the Partnership.

- We are working on a transition plan for the new director. The Task Force is allowing me to stay in my current post until the new director is able to join us. You may have noticed that Jessica Cook is filling in. And we're working on a job description for a new program manager.
- We are getting prepared for the fall meeting. Andie will send out potential dates. We have discussed having this meeting in a series of one and a half hour meetings rather than a day-long meeting. We hope this will be acceptable to everyone and we will send out this information soon.
- Milestones update: Our governance documents are the action framework which outlines goals to 2030, and every year we have a strategic outline that includes milestones. We have included in Monday's email the 1 July version of this milestone. We have removed the activities that have been completed. This version shows the transition plan through October: who will be responsible for each activity and who is working on what. We would like to hire a new staff person as a program manager. This person would focus almost exclusively on developing the country partnerships. They would assess who needs to participate and how things are going to run, monitoring, evaluation, and coordination with local partners. There are a few things we want you to focus on. While we have the NTD framework that includes leprosy, we don't have good indicators for leprosy. It's going to be challenging to put together proposals or other items for resource mobilization if we can't articulate what we're going to accomplish and how we're going to measure it. The second thing we're missing is a robust country model. Our country model right now has a tool for assessing initial capacity. We need a more robust tool that can measure capacity over time. It should include a monitoring and evaluation framework that will lay out to donors what we will accomplish and how we will accomplish that. This should be worked on jointly with WHO. The third item is GLP's 2030 plan. It's unclear what's currently happening with GLP's 2030 plan. It would be great to have information from Erwin on this so that we can link our work with the work of the Global Leprosy Program. Another core item is the Research agenda prioritization. We're grateful to Cairns, Jan, and Arielle for stepping in and seeing this as an urgent need. We had good discussions in Manila, but we saw in our evaluation report that not all the partners are moving toward alignment yet. In some cases, there's a lack of transparency and a pursuit of individual goals. We would like to foster an open discussion about this starting today and moving forward over the next months. This will be challenging, but the partnership is in a place now where you are willing to be trusting and vulnerable with each other.
  - Arielle: Should we share input on the milestones with you by email, or with everyone?
  - Courtenay: Share them with everyone.

### III. Research agenda strategy: Jan and Cairns

- Cairns: The current methods we're using in our leprosy activities are evidence-based and robust. They have been through the review process by WHO's guideline committee. However, they are simply not enough to achieve zero leprosy. Research is a crucial part of the work of the Partnership, looking to develop new, better approaches to be able to tackle transmission, disability, and stigma. We have gone through a process of developing a research agenda and a consultation with over 140 people in the leprosy community. That has produced a list of eight topics which is already prioritized. We looked at other topics. Arielle and I have been looking at the WHO guidelines for prioritizing research agendas. We've already done the prioritization through the creation of the research agenda. Our next step is to go through the Delphi approach to then prioritize our list. Some of that was done last year by the stakeholder consultation. We're at the stage where we need to focus on remaining priorities and review current on-going research, because if we do that, we recognize that there is ongoing research in many of these topics, for example, in digital solutions, modeling, and operational research. We need to identify areas where we're not seeing the same amount of activity, like stigma and disability. We need to go through a process that would prioritize from our list, review what's already going on, and challenge the research community to respond to this issue. The research agenda was approved about a year ago. We now need to come up with a more focused agenda by September. That is our aim. We have a long list within these 8 topics, and we need to look at the ones that will give us the greatest impact, feasibility issues, and where work is not happening. We know what the stakeholders think of the key topics. We need to review it in light of what's happening in current research so that we can come back in two months' time and address where we need to stimulate the research community.
- Jan: The Leprosy Research Initiative (LRI) is an enthusiastic member of GPZL. LRI was in the process of redefining its funding priorities. We managed to align it with the research agenda. We joined Cairns in a bit of concern during this year that the follow-up of the research agenda seemed delayed or stuck. That was a reason for us to step forward and offer help from this experience in the organizing and prioritization process. I shared with you the policy paper of the leprosy research initiative. Our core business is funding research proposals that work toward zero leprosy. We have a limited capacity to fund research, with a budget of about 1.4 million a year to allocate. LRI has been successful in connecting to bigger donors, especially the European and Developing Countries Clinical Trial Partnership (EDCTP), convincing them to include leprosy in an important call in 2018. This opened up 6 million in resources for additional leprosy-related research. We would like to assist the Partnership in prioritizing and setting an implementation plan for the research agenda after the priorities have been agreed upon. We don't only want to fund good leprosy research. We also want to facilitate networking among leprosy researchers. This is why we organize an annual spring meeting in the Netherlands. We invite researchers funded by LRI and other researchers working in leprosy to inspire

each other to develop new plans for leprosy research. We are growing a crowd of leprosy researchers. We think the leprosy world needs this, because we are a small community, but we can do better if we're aligned. There are gaps in our understanding of leprosy that need research proposals. One example was the PEP workshop last year. We had sub-workshops for researchers and for program people. A spin off idea from this meeting is being proposed to a big donor, the EDCTP, to investigate the focal or SDR-PEP. We helped assist this group of researchers, and it is now presented to a donor. We need more breakthroughs in order to achieve zero leprosy. This is an offer that we feel comfortable with, to be assistive to the Partnership. I hope we can find the terms to play that assistive role.

- Arielle: It's clear from our milestones that we want to develop research implementation protocols for priority topics. Our clear next steps are to identify what those priorities are, and we have proposed an objective methodology and a proposed timeline. Now, we need to mobilize the working group and then focus on the implementation plan.
  - It was offered that Dr. Nienke Veldhuijzen, who has expertise in developing research agenda priorities from a similar effort at LRI, could be seconded to the GPZL to coordinate the development of priority-setting and an implementation plan for the GPZL Research Agenda. Terms of reference and a budget for this work will be developed by a small group (to include Cairns Smith, Jan van Berkel, Nienke Veldhuijzen and Arielle Cavaliero) and presented to the LT for approval.

### III. **Governance discussion: Bill Simmons and Courtenay Dusenbury**

- Bill: Our governance successfully got us this far, but it still has some challenges. I hope some of the challenges highlighted in the document I shared might highlight why we need to look again at our own governance to avoid some of the problems that governances face. This is a part of evolution as an organization. The Secretariat has provided us with materials to start this discussion.
- Courtenay: In the email we sent everyone we laid out a process for discussing governance for the next phase of the Partnership. For those of us who were there in January 2018, we were in a phase of thinking this would be a one-year or a two-year partnership. We tried to craft a leadership team that could include major stakeholders and represent the organization as we implemented the major activities of the action framework. Now that the partners continue to grow, we are more focused on three areas of research: agenda, implementation to support country capacity, and resource mobilization. We had the opportunity to look at lessons learned and what is the best structure for the next years. This, the evaluation, and the perspectives of the Secretariat are coming together at a time to give this phase the attention that it needs. We are laying the groundwork not only for ourselves but for everyone who comes after us. The goal of this exercise is the governance of the Partnership. Those who were at the first meeting might remember a great discussion about organizational values, which was

repeated in Greenville. We need to make sure that our values are represented in our leadership team. We should define what a successful organization looks like. Who needs to be at the table? We need to have agreement on the role of the Secretariat and how the Secretariat can support the leadership team. We're transitioning now, and we need everyone to consider alignment and support. Everyone has the same goal, which is zero leprosy. We can think about the composition of the leadership team, its roles and responsibilities, and how we work together with the Secretariat to accomplish this. By 1 October we would like to have a revised charter and a RACI chart. This would show specific responsibilities and give us a way of knowing the involvement and roles in each decision. We would like to discuss this in an hour and a half meeting in about two weeks, and again in September. To help us with this work we should have a subcommittee to work on this RACI once the perspectives of the Leadership Team are made known. It's challenging to be vulnerable, and I want to share more of my personal perspective to reinforce that the Partnership is important to me and to the Task Force. I hope we all reflect on why we're a part of this, and how we can continue to contribute to it. I will continue to contribute in my new role at the Task Force.

- Geoff: I support the process and the timeline that Courtenay has shared. I found the objectives narrower than I'd expected. We need to come up with the right future governance model for the Partnership. The objectives talk mostly about the Leadership Team, and I would have wanted it to be expressed more broadly. If you look at the seven objectives, I was expecting that we would talk about the right structure for the future. Is it to continue to have a leadership team like this? In other words, to ask a bigger question and then focus in on what that means for the Leadership Team. It was interesting to me that when I read the document that Bill sent there were lessons that had to do with hosting. That is evidently a governance question that other organizations have raised as well. It seems that since that has been raised in the evaluation, maybe we ought to find a place for that in the objectives.
- Courtenay: This comes from the RACI document, to see where different levels of engagement are needed. Then we can see what type of board is needed. I understand your point, that there is something missing. We can certainly add that. On the issue of hosting the Secretariat, we've gone over the evaluation. It seems that there are two people from the Leadership Team who have raised the site and hosting as an issue. We need to ask the leadership team if the hosting of the Secretariat is a concern. Or, can we move ahead for the next three years with the current hosting site, and then revisit it.
- Bill: I think we can ask ourselves that question, but we don't have to deliberate about it if we don't need to. Maybe there's a way to frame within the objectives

the outcome, as it relates to governance. Governance is not stated in the objectives clearly.

- Benedict: We need to fit the Task Force for Global Health within our governance structure.
- Jan: It may be good to clarify the roles between the Task Force and the Leadership Team. In many foundations, the board is the employer of the director. I think it's possible to clarify who is responsible for what, and how this impacts the functioning of the Secretariat and the director.
- Mark: I would like the project to look at the broader frame of decision making, beyond the Leadership Team. I think the Leadership Team should be a component in our organization. Maybe we have sub-teams that are a bit more empowered. Then the Leadership Team could vet what those teams do. We should look at the broader way we work together.
- Maarten: The Partnership has different entities, including the Secretariat, the Leadership Team, the working groups, and the members. The roles of those different entities, and who can become members and for how long, should be described in a governance paper.
- Arielle: We should also bear in mind that a governance structure is not supposed to be static. When we think about governance, we should be aspirational. One day the topics being explored by our working groups will need a platform to inform the Leadership Team.
- Taka: We have concerns about the structure of the governance of the Partnership, but we also need to discuss our objectives and activities. I hope we will not only discuss governance structure.
- Bill: We will need dedicated time to further explore this topic. Could we add clarifying questions? We should create participation between now and a discussion meeting.
- Courtenay: We will discuss the best way to capture information to lay the groundwork for the discussion in two weeks. We will come back to everyone.

#### IV. Concluding Remarks and Observations from Leadership Team Members

- José: There's a lot of thought that has been put into this, but there's nothing that references persons who have experienced HD. I understand the objectives, but I think it's important to state that within the objectives. I plan to write something about my thoughts on this subject.
- Mauricio: I'm not seasoned at discussing governance and it's difficult to discuss these issues online, but I will make general comments: one of the most important values of the Partnership is to help countries to achieve their goals. Sometimes I think we are concerned about indicators we want to reach, but I think we need practical experiences.

I am happy that LRI wants to help with the Partnership's research agenda. The Partnership needs to think how it can help countries to solve their problems. We know the problems: the number of cases is not coming down, and contact tracing is not good enough. As a Leadership Team, we are more concerned about rules to be developed by countries. We don't discuss how we can help countries. We can consider offering workshops. We need strong experiences from the field.

- Taka: One of the objectives of the Partnership is to support the countries. We have different roles because we have different strengths in supporting countries. The Secretariat is trying to maximize the roles of all the partners. I appreciate that the Secretariat is transparent about the process.
- Bill: It is difficult to carry out these discussions in a call like this. It may be helpful to use breakout rooms in future meetings to make sure that everyone is able to engage in the conversation. We will explore that for our next meeting.