

**Leadership Team Meeting: Governance****13 August 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
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Alice Cruz, UN Special Rapporteur (observer)

**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

**Invited but unable to attend**

- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (guest)
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis Pharmaceutical
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Mark Alexander Rogers, Senior Global Program Head Neglected Tropical Diseases, Novartis

## I. Welcome: Bill Simmons

- **Bill:** We celebrate the extension of Alice's mandate. Alice's commitment is deep, and she is a volunteer. We're thankful for Alice, and we're sharing our excitement across the world that her mandate has been renewed. Congratulations.

We are here to talk about governance. Governance serves the work of the people. We don't do governance for governance's sake. It's a reminder that the work of the Partnership is the work of the partners. It's important that the partners understand what their work is and that they agree that they are part of advancing the Partnership forward. Governance serves the partners in knowing how they work together. We're not so enamoured with governance that we overlook the more important work. We want to ensure that partners are clear about their contributions toward the shared vision of the Partnership.

We will think through the role of the partner and where that intersects with where we are headed. We've had many meetings over the last two and a half years, and we've discussed governance. Courtenay and her team will help us navigate through the discussion.

## II. Rationale and process for the discussion (through October) & GPZL's Shared Vision: Courtenay Dusenbury

- **Courtenay:** We want to reiterate the process that we will use for planning this over the next month. We will not read the whole slide, but we want to make sure everyone feels comfortable with the organisation. We will give an overview of our objectives. We want to make sure that everyone feels comfortable with the Strategic Outline. Today we want to discuss, What are some of the needed skills of Leadership Team (LT) members, and do we have all of those skills today?

We have a lot of good examples of LT members who have given a lot of effort, and organisations who have contributed a lot to this Partnership, either through Partnership activities or through complementary activities. Each of you on this call has given so much to this effort.

We also want to discuss the Secretariat's role, the activities of the Secretariat, and what role the board wants to have.

Finally, we will discuss the best structure. A RACI is a chart that shows our specific activities, the role of the board, and the role of the Secretariat. You will have a RACI to refer to when there is a question about your role or the role of the Secretariat.

We also want to remind you that we have an Action Framework. The goal of the Action Framework is to meet World Health Organization (WHO) and national targets by 2030. We agree on the long-term goal, which is Zero Leprosy. And we have three major objectives. One is accelerating progress on research agenda priorities. We also work in partnership with national programmes, mobilising resources and building advocacy. This includes building the capacity for advocacy of persons affected by leprosy.

- **Andie:** We're moving into breakout groups to discuss topics related to governance in small groups. We will come back together as a larger team to share our impressions. As Courtenay mentioned, this will be a conversation about the attributes and composition of the Leadership Team.

### III. Breakout Discussion 1:

*In small groups, LT members discussed the following questions concerning the research agenda, national programmes, and resources mobilisation and advocacy, and then reconvened to share their ideas.*

*Question 1.1: For each of the three objectives, what specific LT knowledge, skills, attributes, influence (political/social/organisational level/donor connections) or characteristics are needed to achieve our stated goal?*

*Question 1.2: For each objective, do we currently have the knowledge, attributes and influence needed on the core LT (not advisors, just LT members) to achieve it? If not, what are the gaps in skills/attributes/influence for each of the three objectives? What additional skills or perspectives could be added for each objective?*

**Group 1: Cairns, Taka, Bill, Alice (Notes: Courtenay)****Courtenay summarises:**

- **Research Agenda:** Cairns has given so much attention to the prioritisation and Research Agenda. This group thought that we could have a more robust human rights approach to disability by including someone who is in that field: a health worker or representative that works at the sub-level instead of just at the higher level. It is hard to get national leprosy programme managers' (NLPMs) time because they have many priorities.

Especially for the research agenda, we could have more national programme and expert participation, such as people working in disability, because they are using the WHO guidelines.

- **National Programmes:** For the second objective, additional NLPMs and experts could be helpful.
- **Resources & Advocacy:** Lastly, for resources: It was thought that the perspective of people who have raised money for challenging problems where there is low awareness would be good to have on the board. More conversations with persons affected so that we can bring successful organisations together in some way. We also talked about a strategy of ownership and capacity building for persons affected.

When we came to advocacy, we discussed building a stronger voice for organisations of persons affected. The Human Rights Council is strong in elevating a voice for persons with disabilities, and we don't have that strong voice yet.

In the last column, we discussed different perspectives we could add. At the political level, we need to amplify Sasakawa and Alice's mandate. We could expand the LT into disability and engage with the media. We need to understand existing initiatives, particularly from the Sasakawa Health Foundation, and then find the niche for the Partnership.

**Group 2: Geoff, Benedict (Notes: Andie)****Benedict summarises:**

- **Research Agenda:** We need people who are well-grounded in research, and Cairns is one good example. We need people who move from that point into strategic thinking about fitting into country systems and linking with academic networks, such as universities. The first group mentioned something similar, for the second objective.

When it comes to academic engagement, we want a North-South academic perspective. University networks may already have that established. We could leverage this in countries to bring all researchers together with programmes on one page. We want to work in countries with national government programmes, but we also need to involve persons affected. When it comes to advocacy, we look at persons affected again because we have to amplify their voices, as the first group also said.

- **National Programmes:** For national capacity, we need to broaden the influence of French West Africa and Indonesia. We don't talk a lot about Indonesia because there is no one from Indonesia represented, for instance. We need to broaden our coverage.
- **Resources & Advocacy:** Communication is an essential skill. Having more representatives means that we'll be able to reach more people in terms of advocacy. We need to build relationships with organisations we want to reach out to. For relationship building, we need people to pull us into some of the organisations. We could get more academic involvement, such as groups of universities in the UK who may also have links with universities in the Global South.

We also need a stronger donor perspective. We should look into getting the voice of a large funder in the health sector. We also need to strengthen our political connection.

**Geoff Warne:**

- We've got a broader representation, but there are two types: the board representation and persons affected organisations. There's this question of representation from outside. It will challenge our thinking. For example, bringing in a major donor organisation, one that doesn't fund leprosy, could make us think differently.

**Group 3: Jan, Mauricio (Notes: Caroline)****Jan summarises:**

- **Research Agenda:** Regarding the Research Agenda, we need to discuss complex scientific issues. We won't all have these skills, so we need well-prepared issues for decision-making. As we consider the LT as the highest decision-making body in the Partnership, such important decisions on research priorities need to be prepared by a working group. When we look at what we might be missing in the function of the prioritised research agenda, we think the scientific community and others like Leprosy Research Institute (LRI) are well-represented. What we missed also relates to the national programmes column: a discussion on Benedict's proposal.

Additional perspectives could be added for the Research Agenda. It's important to keep extending the network of leprosy-related research. For those of us who are not researchers, we can connect to national networks. For a more general understanding of leprosy-related research, we could have updates from speakers, for example, Cairns from the scientific community. Sometimes researchers are organised at national levels and are connected to national programmes; sometimes they are not. We need to be aware of the sometimes political settings in which research is organised in countries and the specific challenges per country. We need to have mechanisms to monitor progress, not only at country levels but also for the Leadership Team. Focusing on persons affected: we need to reach out to them to understand their agendas.

- **National Programmes:** To increase the effectiveness of national leprosy programmes, we could look into our Theory of Change. We want effectiveness at the national level, but we see different positions between national programmes and our partners. It may be good to be explicit about the roads to work toward more effectiveness at the national level.

We need to increase the alignment of national programmes to the Partnership. We appreciate the input of Mauricio and Benedict. A few weeks ago, Benedict shared a proposal for forming a subgroup. That would take care of interaction with national programmes who themselves are not directly represented in the LT. The LT could then speak on behalf of a wider community of national programmes. Benedict's proposal has not been discussed yet, and it fits very well into this governance discussion.

We need to be open to specific challenges per country. We need to encourage countries to analyse their challenges and how they can achieve the goals toward zero leprosy. We need to encourage them by listening to the people in the field and learning about the barriers to success.

- **Resources & Advocacy:** As for resource mobilisation, we should consider a subgroup structure for the representation of persons affected on the LT. We appreciate the input usually given by José, and we can think about how to organise representatives—the many groups on national and regional levels—as Sasakawa Health Foundation has done. We also need to develop communication between various groups of persons affected.

We also want to discuss proposal development for donors. One point, which is already a priority in the leprosy community, is to advocate for big entity donors to not only focus on the five PC-NTDs but to include the whole community of NTDS, including leprosy. Now donors discuss going with 19 NTDs. Again, there is the thread that they will only focus on five. We need to make efforts for them to include leprosy as part of the whole challenge of 20+ NTDs.

We have focused on the big proposals, but there's a place for us to look for opportunities for smaller proposals. We are aware that we discussed earlier that the Partnership should not become a competitor with members who are raising funds, but it can inform members about opportunities that arise with particular donors. We would like to add the perspective of Courtenay, with a focus on her efforts toward federal government funding in the U.S. We know that she's taking that message from the Partnership, to include leprosy in donor funding options. Let's keep in touch with Courtenay in her new assignment.

- **COVID-19:** What we did not elaborate on, but realised before closing time, was that we need to be aware that COVID-19 is going to affect our ambitions and efforts for quite a long time. This will be an additional challenge for everyone involved.

**Mauricio:**

- I want to add that within the LT, we have different people with specific skills in different areas. We do not always share everything with everyone. For example, Jan said that we could have a meeting about the research agenda, or update everyone about different donors. It's more about sharing where we are in each of the three objectives with everyone.

**IV. Summary: Courtenay Dusenbury**

- **Courtenay:** We want to thank everyone for this rich discussion. We will move the second breakout discussion to the 2 September meeting. We will discuss more as an entire group now and move the second question to next time.

Looking at the three objectives of the LT, we heard some good comments about what is missing from the LT. Are there specific areas for the research agenda priorities, country work, or resource mobilisation, where you need someone on the LT or a group that LT can report to? Comments/suggestions on that? For example: We are re-establishing the Resource Mobilization working group. Should we reinstate the research group as a way to inform people? Should we have a working group on the country projects that can be a source of information for the LT that feeds through LT but doesn't necessarily expand the LT?

- **Cairns:** Related to Mauricio's point, we could have a greater degree of exchange. We need to share from each of our organisations, as many LT members are here representing an organisation. We need to be aware without finding out by default.

In terms of research and people who are knowledgeable about interventions, we need to rebalance ourselves. We are highly focused on the disease interruption or transmission element, but we're not as strong around disability or interventions that would reduce discrimination. People and institutions and universities in our common area of work are doing this. Disability intersects with other NTDs and other disabling conditions. This would be relevant, but it is outside of the scope of our vision at present. The same goes for discrimination. People who are doing work in that will be doing work on mental health. But we need to interface with that and share ideas.

- **Geoff:** As Cairns has said, we want to hear those perspectives. Otherwise, we easily miss what is going on in the wider world. All of the groups mentioned this today: countries' perspectives, organisations, persons affected, and likewise. Not only on the research base—understanding the disease and challenges around Zero—but also in disability, stigma, and discrimination. We need people who aren't the usual suspects: people outside of what we normally think when we think of people who are committed to zero leprosy. Alice already does this for me. And I think there are other excellent voices. Cairns just mentioned some. Or, we try to do what Jan and Benedict have talked about: setting up smaller structures. Smaller structures can be part of the Partnership and talk about certain issues, with other voices. Then there's someone who brings their perspectives to the LT. I prefer the more direct approach, but the number of participants has to be limited. Otherwise, the LT is massive.
- **Courtenay:** It would be interesting to look at other organisations to see how they have handled this. There is a balance between wanting the perspectives and having a 20-person LT. It would be interesting to have a smaller group to bring some of these voices in. Jan and others have suggested a smaller executive team and a larger Leadership Team, which could bring in the voices. It's interesting for you all to think about as you move forward. We have seven minutes left for any comments.
- **Mauricio:** I think we could discuss Benedict's idea about a group of national programme leaders in the future. I hope we are moving toward a more practical phase of the Partnership by working with countries more specifically. We will have field experience, and it would be interesting for those programme managers to share their problems and their experiences, and how they see the Toolkit, for example. This would be thinking about how to create a group among those programme managers to discuss the practical experience of the Partnership. Benedict and I are here as council representatives, but our experiences and ideas differ from the practical experience of the countries that the Partnership is starting to work with.
- **Cairns:** For the last 20 years, national groups had regional meetings of national programme managers with Southeast Asia and the Western Pacific. It may be developed on WHO networks and common issues within a region. There is a lot of exchange of ideas in these meetings, so that's a format we might want to explore with Erwin.

- **Andie:** I will mention that we spoke about that format in our group, and Benedict had some great ideas about its utility and its limitations, and the ways that the Partnership could build on it to make it more effective. At a later date, or by email, I would like for Benedict to share his comments with the group because they were insightful.
- **Bill:** I like the notion that Mauricio and Benedict suggested, that the formation is driven by national programme managers, with all due respect to the WHO structure. We have seen high engagement from national programme managers in the MDT working group during COVID-19. I think there's an opportunity to take advantage of both.

**V. Concluding remarks: Bill Simmons**

- **Bill:** This is Courtenay Dusenbury's last team meeting. I am thankful for Courtenay's investment in the Partnership and in all of us. She has done a great job in launching the Partnership with us. She has done a great job of helping us walk this journey toward a shared vision and goal. I commend your commitment to this work. We are really thankful for that.