

Leadership Team Meeting**5 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
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (guest)
- Alice Cruz, UN Special Rapporteur (observer)
- Mark Alexander Rogers, Senior Global Program Head Neglected Tropical Diseases, Novartis (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- David Blok, Researcher and Mathematical Modeler in Infectious Diseases, Erasmus MC
- Mathias Duck, Chair, ILEP Panel of Persons Affected by Leprosy
- Amar Timalina, President, IDEA Nepal
- Rekha Shukla, Joint Secretary, Ministry of Health and Family Welfare, India
- Dr. Rao Pemmaraju, Technical Officer, WHO Global Leprosy Programme (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

- 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)
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana

I. Welcome and update: Bill Simmons

- **Bill:** Welcome. To start our agenda, we invited the WHO Leprosy programme to give us the update on their strategy.

II. WHO Update - Leprosy Strategy & Activities: Dr. Rao Pemmaraju

- **Dr. Rao Pemmaraju:** This was a good opportunity for us to share about what's happening in the Global Leprosy Programme (GLP) and give updates on key events. There are 4 topics: technical guidance about national programmes, sustaining expertise in health staff, monitoring data management, and global leprosy strategy. In the area of technical guidance, GLP prepared a guide to manage reactions and prevent disabilities. This has been received well in terms of its use. It's now being translated into Arabic, French, Portuguese, and Spanish.

A draft on technical guidance on contact-tracing and post-exposure prophylaxis (PEP) has been submitted for review. We're expecting feedback on 7 August and it will be released at the end of August for dissemination. Both documents will be available on our website. Partners are free to share them. I thank the Leadership Team for giving feedback on technical guidance on contact-tracing and post-exposure prophylaxis.

In addition to this, we contributed to technical guidance for country programmes in the context of Covid-19 for implementing and restarting population-based surveys on neglected tropical diseases. Our interim guidance is available now on the site, and we've had discussions with Working Group 3 about how it needs to be translated for leprosy programmes.

- **Support for national programmes:** Regarding travel restrictions, repurposing of staff, and other challenges in the context of Covid-19, GLP is planning to extend support to countries through local consultants on the ground. These consultants can be supported remotely. These consultants are supposed to help countries in developing national strategy plans and monitoring. First we are working with Timor-Leste. The national programme is doing very well. We're trying to look into hiring professionals so that countries will have some people who understand leprosy.

- **E-learning modules:** E-learning modules are being developed to respond to reviews from national programmes in different countries. There are four modules already in English. These are being translated into Arabic, French, Spanish, and Portuguese. These modules cover: suspect and referral, diagnosis of leprosy, treatment of leprosy and counselling. In addition to these four modules, four more are in the process of developing. They cover areas of treatment of reactions, prevention of disabilities and physiotherapy, self-care and laboratory diagnosis in leprosy.

In total there will be eight modules. Four are already on the GLP website. Once the inputs are received from peer-reviewers, we'll be able to release the next four at the end of September 2020. These modules will also be translated. We're planning to host all eight modules on the openwho.org webpage, which has a built-in learning management system where we can track how many people have used them and receive continuous feedback. These eight modules will be available by the end of the year. Partners can host these modules. These will be presented in the ILEP meetings in September, and there will be an opportunity for people to review.

- **Monitoring and data management:** The data from 2019 is in process. We have received data from 146 countries. The total number of new cases is slightly above 200,000. It appears that Covid-19 did not have a great impact because it appeared in December in several countries, but not until March in some countries.

The data collection was done through the DHIS2 application, which also has provision for sub-national level data entry. This year we did not get permission from all countries, so we did not ask all countries to include data for sub-national levels. By 2021 we expect that countries will permit us to view sub-national level data. It will be easy for us to monitor data up to the first sub-national level, as applicable for each country. This year we're also going to synchronize the MDT requests and reports so we can see the number of cases detected.

- **Global Leprosy Strategy 2021-2030:** The Global Leprosy Strategy has been drafted with four pillars: developing country-owned zero-leprosy plans, stop leprosy and its complications, prevention of leprosy with PEP, contact tracing and early detection, and combat stigma in partnership with persons affected by leprosy. The targets are in line with the NTD Road Map 2020.

- **Task force for the certification of elimination of leprosy:** This task force has identified seven topics to be discussed by including people from outside of the task force to get wider inputs. Three meetings have been completed. In the first meeting we discussed the phases that a leprosy programme has to go through before reaching elimination of leprosy and criteria for readiness to move into the next phase of leprosy elimination.

The second topic discussed was definitions of concepts concerning interruption of transmission and elimination of leprosy as a disease. These sub- groups will report to the task force. By the end of November the task force will make recommendations. Some of these definitions and indicators for elimination will have a place in the global leprosy strategy.

III. **Research Agenda: Cairns Smith**

- **Cairns:** This is an update about progress with the research agenda and working out a process of prioritization. The WHO guidelines offer two approaches to prioritizing research. There is the stakeholder consultation, which has already been completed and gives insight into zero leprosy, zero disability, and zero discrimination. The second approach is to create a matrix with the research topics. In the process of extracting detailed research questions from the report of the research agenda process and then to assess each of the research topics against the criteria: how critical it is, how long it would take, its cost and feasibility, and an assessment of the likely impact and the impact on achieving zero leprosy in relation to other NTDs. We're in the process of creating that matrix.

We want to ask the members of the Research Agenda Working Group—particularly the facilitators of each topic—to rate each of these criteria in terms of low, medium and high so that we can create a prioritization process. We hope to do this over the next month and present the final process to the Leadership Team in October. The people working on it are Jan van Berkel from LRI, myself, and Arielle from Novartis.

IV. Country capacity-building/ status and modeling: Andie Tucker & David Blok

- **David:** The aim of the modelling is to support research mobilization for leprosy interventions. Hopefully the outcome of this modelling will be helpful for country partners but also for future fundraising and research mobilization. This far, we have discussed who and what should be modelled in the coming 6 months. We agreed that we will focus on the countries that we planned for review this year. This includes around 14 countries. As a second step, we consulted around the outcomes and interventions that should be included for the purpose of the modelling. We decided that our main focus should be on new leprosy child cases. This is a key objective for most donors and stakeholders. If we could show progression toward a reduction in new leprosy child cases, this would be very helpful. As another outcome, we include any new leprosy cases.

The third important outcome would be the resource savings. We want to show that we can reduce the incidence but also increase future resources. This would include cost and cost-saving associated with the model's impact.

For interventions, we will include SDR-PEP. It's a tool that's available and still not implemented everywhere. We want to show the relation-based approach for individuals in endemic pockets. As a second preventive intervention, we would like to include diagnostics. Diagnostics are important especially within NTDs. With modelling we want to illustrate the potential added value of diagnostic alongside SDR-PEP. We would like to demonstrate what it could mean for the end game of leprosy. We will also focus on sub-national levels within countries.

- **Andie:** A working group will provide feedback on the modelling work that David has described. The membership will include country representatives, like National Leprosy Programme Managers or folks on their teams; partners involved in research mobilization that can speak to international donor concerns and priorities; and members of the GPZL Leadership Team. Benedict has already volunteered to be part of this group. We would like to open this up to others on the Leadership Team. We appreciate your suggestions of folks on your teams that you think would be a good fit for this group. Everything David has explained has been compiled in a TOR that we worked on this week. We will send it out on Monday's LT update.

- **Maarten:** With each country, you come up with different key interventions. Will you include BCG coverage among children or adults?
- **David:** Yes, the modeling this far does include an assumption about BCG coverage, but it is not a separate intervention.
- **Maarten:** Could it be a separate intervention?
- **David:** The model includes BCG alongside SDR. For this modelling purpose we do not want to include it separately.

V. Working Groups 1, 2, and 3

Working Group 1 (WG1): Courtenay Dusenbury

- **Courtenay:** WG1 (the MDT group) had a meeting on Monday. We have drafted a commentary for Leprosy Review on the process that WG1 used, a survey, results summarizing the survey, and recommendations that can be passed on to WG3. There will be time to look over the outline until August 7. The group will work together on this commentary, hoping to have it finalized by the end of this month.

Working Group 2 (WG2) : Alice Cruz and Amar Timalisina

- **Alice:** This has been an amazing experience for me because I am used to working alone. The efficiency and the advice have been amazing. Courtenay has already updated you on our main activities in the email she sent on 27 July. We held a consultation with organizations of persons affected and organizations that work closely with persons affected from all over the world. We consulted more than 25 organizations and over 100 individuals.

I sent a letter to the UN Member States. We also produced a report with recommendations. The recommendations that I sent to States are much more demanding than the ones we have produced for civil society organizations. The main features of the recommendations are that relief should be linked to the promotion of development activities.

This report is going to be submitted for publication at Leprosy Review. After that, we decided to share responses from the questionnaire that you all received about the protection of persons affected during this crisis. We received about 100 responses. We will now analyze these responses to produce an objective fact sheet. We can use the fact sheet to see gaps, and persons affected can find information on support that is being provided in their countries.

We will also be producing two videos. The first one will be based on my letter to governments. I will be the main narrator, but I proposed the group to include six women affected to help me narrate the video. We're very excited about this one. The second video will be focused on the experience of persons affected during this crisis.

I would like to highlight an important aspect that Courtenay mentioned in her email, regarding our work. Our group was able to establish an important bridge between organizations of persons affected and individuals who do not participate in any organization but are very committed to producing change. We have reached these groups with the GPZL in an efficient manner.

Speaking as a Special Rapporteur, we've also witnessed how these groups are able to engage in a common dialogue. Without their participation, we wouldn't know what is going on on the ground during the Covid-19 crisis. This has shown the importance of their participation in any process, especially in finding solutions to problems. We've also witnessed that these groups are ready to engage in an international dialogue among themselves. We've also seen the birth of specific groups. I'd like to highlight the group of women affected. Due to this process, they are starting to organize in an informal manner. They will have a meeting to discuss the call for the ILEP panel of persons affected. This is an important outcome to which I call the attention of the Leadership Team.

- **Amar:** I want to give thanks to Alice and the entire WG2 team.

Working Group 3 (WG3): Taka Nanri and Geoff Warne

- **Taka:** We had a couple of meetings in the past few weeks to discuss the direction of WG3. All of us agree about the importance of WG3, to ensure the strategy for the future. At the same time, it is difficult to predict what post-Covid-19 looks like. We decided to concentrate on this question: What should be the next step taken by WG3? In order for the Partnership to respond to the needs of the country, collaboration with WHO GLP is essential, and duplication of the work between WHO and GPZL should be avoided.

We have come to conclusions that we should start focusing on 10 countries, already certified by the Partnership, given that the situation is different country to country, and the standard guidance may not be applicable. The Secretariat will contact WHO national offices in several countries and set up meetings with the national programmes. We can also include other key stakeholders to discuss actions to respond to the needs.

In-country working groups consist of key stakeholders to conduct detailed discussions based on these initial strategy meetings. We can start taking the bottom-up approach. We needed a clearer image of the global strategy to respond to Covid-19 based on the initial strategy meetings in 10 countries.

- **Geoff:** Working with the government doesn't come in a vacuum. There are a number of organizations that produce advisory documents on how countries can continue, restart or manage NTD programmes during Covid-19. As a working group, we are devoted to the WHO interim guidance for NTDs as a whole. The Bill and Maria Gates Foundation is about to launch a series which is called, "Adapt, Accelerate, Integrate, Optimize." Those are four different views on how to run programmes during the ongoing Covid-19.

We are asking, What do national programme managers really need? That's what Taka discussed, working with these teams. Maybe we'll be able to take what's being produced at a senior level, make it usable, and see what we can do with other countries.

- **Dr. Rao Pemmaraju:** We discussed a dialogue about Covid-19 with national programmes. We discussed utilizing local consultants. We also discussed last month the distribution of MDT. Another thing that came up during our discussions was the role played by persons affected by leprosy and their families.

This needs to be explored much more because travel restrictions are so high, and persons affected are an important resource for us. We need to ensure care and cure for persons with disabilities.

- **Geoff:** One of the things about the guidance is that it's generic. It talks about how we can do the things we were doing before, but in a safe way. However there were some innovative ideas being trialed by different countries, and that's what we want to build on. How can we use what national programmes have already experienced and see how that thinking can be applied to other countries as well?

VI. Milestones Update & Plan for Governance: Courtenay Dusenbury

- **Courtenay:** We will meet on Thursday, 13 August to discuss our organizational structure and governance. We will send out the notes again, including some of the meeting notes about our previous governance discussions to reorient folks with the decisions and commitments that you have already made. We will do the meeting on Zoom so we will see each other, and there will be breakout discussions. We originally planned this discussion for London in March, but we hope to have more face-to-face discussions over a couple of meetings on Zoom. You will all move this into a discussion about strategic planning, which will take place during your meeting in October.

We are hiring a project coordinator, and this individual will oversee the coordination of the 10 country efforts. This person will work closely with the Partners and with WHO to get this started, being in touch with countries to find out what's needed, and developing a plan for working together. We have whittled it down to five individuals' resumes, which I will send to you. We will interview them next week. We will narrow them down to three candidates. The new Secretariat Director, Bill Gallo, and I will make the final hiring decision.

We are working on our new budgeting and milestone updates. We look forward to presenting those to you next week, as well as discussing the organization's alignment, commitments, and roles and responsibilities.

VII. Concluding Remarks: Bill Simmons

- **Bill:** We have been meeting on Wednesdays for several years for this call. We're sending a survey out by email. It's a simple survey asking about the ideal day to make sure that we're still accommodating everyone's schedule. Any final comments?
 - **José:** Does the country capacity building include capacity building for individuals who have experienced Hansen's disease?
 - **Courtenay:** In our action framework, we state that including capacity building for persons affected is a priority. We have been working on that separately from the modelling activities with David. We are trying to assemble discussions with organizations. We've had conversations with Mary O'Friel already about what kind of capacity groups would like to have, and we will begin having these discussions with the resource mobilizers including Andie and Julie Jacobson to see what strategies could we put in place to build capacity of persons affected. It's important and we've been focusing on that in our research mobilization discussion. We welcome further questions.
 - **José:** I want to share with the group that we continue with the Friday Zoom gatherings, and the participation continues to increase. We're glad we can make contact with so many individuals on a weekly basis.
 - **Alice:** Regarding the monthly meetings, are they supposed to be held at the same hour?
 - **Bill:** Yes, same time of day. We are assessing the day of the week.

We're looking forward to the meeting on the 13th. It will be the day before Courtenay's last day. We will see you on Zoom in just a few days. Thank you.