

Leadership Team Biannual Conference

17 - 18 March 2021

Participants

Leadership team members and guests

- Alice Cruz, UN Special Rapporteur (observer)
- Amar Timalcina, President, International Association for Integration, Dignity and Economic Advancement (IDEA) Nepal
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Gangadhar Sunkara, Senior Global Program Clinical Head, Novartis
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Linda Hummel, Chair of Executive Group, Leprosy Research Initiative (LRI)
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (guest)
- Mathias Duck, Chair of ILEP Panel of Persons Affected by Leprosy
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Programme
- Nienke Veldhuijzen, Technical Officer, Leprosy Research Initiative (LRI)
- Pat Lammie, Director, Neglected Tropical Disease Support Center
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Wim van Brakel, Chair, ILEP Technical Commission (ITC)

Secretariat

- Andie Tucker, Project Manager, Global Partnership for Zero Leprosy
- Bill Gallo, Secretariat Director, Global Partnership for Zero Leprosy
- Caroline Cassard, Communications Specialist, Global Partnership for Zero Leprosy
- Mondie Tharp, Project Manager, Global Partnership for Zero Leprosy

Invited but unable to attend

- Rao Pemmaraju, Technical Officer, WHO Global Leprosy Programme (observer)
- Rekha Shukla, Joint Secretary, Ministry of Health and Family Welfare, India

17 March

I. Resource Mobilization Discussion: Pat Lammie

Action items:

- Set milestones to hold ourselves accountable regarding Research Agenda and Country Model
- Decide: Should we focus on moving the needle with USAID and Foreign Commonwealth and Development Office (formerly DFID) or focus on internal funding?
- Focus on identifying funding for support for PEP and disability- and morbidity interventions

- **Pat Lammie:**

Existing donors: The Morbidity management and disability prevention (MMDP) door allows for integration of LF activities with leprosy disability programs. Opportunities exist for operational research and program implementation. NTD programs across PC NTDs show potential for convergence of surveillance efforts, identification of “hot spots” and targeting communities. For PC NTDs we have 2 major donors involved in supporting program implementation on a large scale: UK Aid and USAID. It would be useful to bring in additional bilateral donors.

Importance of DALYS: A number of donors prioritize decreasing transmission of NTDs. With the new NTD road map, the NTD community is increasingly focused on developing high-quality diagnostics. There is an opportunity to push for leprosy to be included where there’s a differential diagnosis (e.g., with PKDL or other skin NTDs) involved in treating patients. Focusing on DALYS may not be the most effective strategy.

Other funding models: USAID announced new funding for a malaria version of COR-NTD called PMI INFORM. Other partners are deciding if they’re going to co-invest. If there could be an anchor donor to create a similar research consortium for leprosy, you could follow that model.

PEP Considerations: Under the umbrella of mainstreaming and integration, is there an opportunity to include PEP? The narrative around leprosy is powerful, especially around stigma. The selling point can be ease of implementation or a short timeline to achieve success as opposed to prioritizing cost-effectiveness. The Chagas and leprosy communities are on parallel tracks. We need to build from the strategy outwards to promote integration rather than from the disease inwards. Funding for support for PEP and interventions focused on disability and morbidity as single disease efforts is likely harder to find.

Regional Focus: The pathway to another bilateral donor could be through USAID or UK Aid and their outreach to potential partners. Africa represents specific opportunities. There also are opportunities from donors from the Middle East who are targeting Muslim majority countries. We may want to think about how to get this community to support a broader NTD and global health agenda. There may be special cases where support could be redirected. Current funding is focused on Africa. It's important to work across NTDs.

II. One-time Funding Discussion (Continued from February)

Action items:

→ A working group led by the Secretariat will revise the concept note and report back to the LT. Ganga is interested in supporting this.

◆ Considerations:

- Hear the demands of the main beneficiaries—governments.
 - Share a model to show impact, especially in the reduction of transmission.
 - Address: How long do we need to support a country to show impact?
 - Acknowledge the impact of the pandemic in the creation of action plans
- **Bill Simmons:** It feels abstract because we don't have a specific real-world situation that we're considering funding. How much pressure do we need to put on getting specific?
 - **Bill Gallo:** We have to decide how much we should have figured out before we've seen any action plans, which would be the most significant informant for using the funds.
 - **Bill Simmons:** Would we use these funds after we see certain outcomes of the action plan? Do we support the concept and trust the Secretariat would report back to the LT after the action plans are developed?
 - **Arielle Cavaliero:** The model is being piloted. This funding is an enabler. Perhaps a small working group led by the Secretariat would help soundboard these ideas and then report back to the LT. Another area to consider is sustainability of the funding and the role of resource mobilization.
 - **Geoff Warne:** Countries are looking for sustained funding. I'm wary of an investment that only applies to the first 10 countries and not future country partners.
 - **Maarten van Cleeff:** We should stick to 1 -2 specific areas of concern so we can grasp the results and share lessons learned that would benefit other countries.

- **Gangadhar Sunkara:** We should pick one or two countries that we believe need stimulation rather than request proposals. We need systematic criteria. I want to jumpstart some activity.
- **Takahiro Nanri:** We need to hear the demands of the main beneficiaries: governments.
- **Mauricio Nobre:** We need to prove that our support is impactful in an area, especially in the reduction of transmission. In one year, we can not show impact on transmission. PEP has been seen as an important innovation for leprosy control. We need to think, how long will we need to support a country to have an impact?
- **Alice Cruz:** How can the impact of the pandemic be acknowledged in the action plans?
- **Wim van Brakel: (Chat)** By monitoring and reviewing the situation in areas where PEP was implemented early, we can demonstrate the impact of SDR-PEP at the district/population level.

III. Governance

Action items:

- Small committee will create new description and criteria for LT scientific representative, interview candidates, and report back to LT with finalists
- Description of role will be added to the Charter
- LT will vote on scientific representative in April meeting
- LT will transfer the role from Cairns to the final candidate in May meeting

A. *Leadership Team Chair*

Bill Simmons was reelected as Leadership Team Chair for a second 2-year term. LT members agreed on the need to prepare the next Chair during these coming 2 years so that someone new is prepared to take on this role.

B. *Scientific Representative*

Summary: LT members agreed that a clearer description of the role is needed before making a decision. Process and criteria suggestions are as follows:

Working group: Linda, Benedict, Arielle, and Wim will form a small committee and work with the Secretariat to develop precise criteria for the role of LT scientific representative. Neinke could

also be engaged in this process. The committee will create the description, prepare questions, screen the candidates, and report back to the LT with 2 - 3 finalists. The LT will vote on the final candidate in the April meeting. The role description will be added to the Charter. Cairns and the new representative will be invited for a formal transition in the following LT meeting in May.

Criteria suggestions:

1. Fulfill 3 needs: 1) LT role and working group support, 2) experience in basic research and operational research, 3) someone who can enable us and push the Zero Leprosy Research Agenda forward.
2. Diplomatic; be a good connector
3. Have an academic affiliation and an overview of the current research field
4. Potential to drive science and innovation to help us accomplish the mission of ending transmission, rather than individual contributions as a scientist in the field
5. Sufficient knowledge of all aspects to support leprosy research, including the clinical and social aspects

18 March

I. Landscaping Work: Dr Nienke Veldhuijzen and Linda Hummel

Action items:

- Identify a dedicated focal point who coordinates research work and holds us accountable
- Provide more international collaboration to improve research in endemic areas
- Focus on solving the big problems and gaps, not just a wide variety of research
- Create timelines for initial workshops

- **Arielle Cavaliero:** How do we ensure that we have the right focus to move these planned activities forward? We need a dedicated focal point who coordinates the work and holds us accountable so we can build momentum this year.
- **Bill Simmons:** If I'm giving an elevator pitch of what's next in the Research Agenda, what 2 - 3 points should I highlight?
 - **Nienke Veldhuijzen:** Operational research is an important area to further develop research questions and prepare protocols. Second, we must publish the prioritization and landscaping findings so that that is available to the research community.

- **Arielle Cavaliero:** By the end of 2021, we should have 2 - 3 research publications submitted. We are using the Focal Mass Drug Administration (FMDA) model. We're emphasizing the role of resource mobilization to decide where to submit.
- **Wim van Brakel:** Under the Zero Leprosy Research Agenda, operational research is focused on solving operational problems in a program setting. We need to focus on solving the big problems and gaps, and not just a wide variety of research.
- **Gangadhar Sunkara:** Can we conclude that the world is not doing the right research for eliminating leprosy?
 - **Nienke Veldhuijzen:** We prioritized the research needed to reach zero leprosy, which was set in the framework of the Action Framework and the NTD Road Map. More basic science on the scientific understanding of *M leprae* is important. But in the context of the prioritization timeline, this will take longer than 2030 to answer.
 - **Gangadhar Sunkara:** Beyond organizing a workshop and publishing findings, how can we catalyze this research? How can we identify institutes to sustain this research?
 - **Nienke Veldhuijzen:** The prioritized Research Agenda gives us material to lobby and advocate for funding, but it needs to be taken forward.
 - **Bill Simmons:** The right person in the research representative role on the LT would have strong academic connections to help ensure that institutions take on this research.
- **Mauricio Nobre:** GPZL could provide more international collaboration to improve research in endemic areas. Within the Country Model, the operational research could be stimulated. A research project should allow for an international board of scientists that could review the project and build collaboration. Funds need to reach researchers in endemic areas.
- **Wim van Brakel:** LRI has a stated objective of capacity strengthening of researchers, particularly in endemic countries. I envision we could 1) identify the topic area, 2) call for interested researchers, 3) drive the research and design proposals. Everyone interested would have the opportunity to participate.
- **Linda Hummel:** Within our 2021 workplan and the workshops on our agenda, we should maintain focus on the practical action needed once causes and funders are identified.

- **Arielle Cavaliero:** We hope to have 1 - 2 good ideas to move forward with a smaller group that would draft a one-page concept note. We must create timelines for initial workshops.

II. Country Work Update: Mondie Tharp

Action items:

- Secretariat will provide more information to LT about stakeholders' roles in each country
 - WHO representatives will share information from visits to Cote d'Ivoire, Mozambique
 - Integrate country plans into NTD master plans by identifying what can be done in an integrated way and which actions should be disease-specific
 - Create a transparent process to engage consultants/reviewers
 - ◆ LT will support Secretariat's efforts to pair less-seasoned- with more-seasoned reviewers
 - Further develop the resource mobilization and advocacy components
 - ◆ Engage international partners for resource mobilization
 - ◆ Utilize existing resources more effectively
-
- **Takahiro Nanri:** Next time when you share the progress of each country, you can show us who does what. In some countries, NGO presence is limited.
 - **Bill Simmons:** Engaging international partners is needed for resource mobilization. We need to advocate for funding from international NGOs that might have their own 3-year plans.
 - **Maarten van Cleeff:** Local ILEP officers have to make their own activity plans. This is an opportunity to engage them from the start. Is there a transparent selection process to engage consultants/reviewers? Maybe we have a database where people can post their CVs.
 - **Andie Tucker:** When the Operational Excellence Working Group moved to its next phase, we requested interest in being reviewers. There was not much interest. We need to involve folks who were a part of that group and pair less-seasoned reviewers with more seasoned reviewers. We have made an effort to build this cohort and look to you all for support.
 - **Wim van Brakel:** Before we make the plans on the ground, we should identify what can be done in an integrated way and which actions should be disease-specific.

- **Arielle Cavaliero:** We need to further develop the resource mobilization and advocacy components. It's important to understand MoH and the Ministry of Finance.
 - **Takahiro Nanri: (Chat)** We need a "champion" in each country who can be influential enough to balance interests of different SHs.
- **Erwin Cooreman:** We will share information from our visits to Cote d'Ivoire and Mozambique.
- **Bill Simmons:** ILEP members have unrestricted funding. We need external CEOs of ILEP members and others who can make discretionary funding decisions to mobilize from within.
- **Bill Gallo:** The Secretariat has discussed a concept note for high-level government meetings.
 - **Benedict Quao:** It's difficult for a programme manager to get the attention of other ministries. That's where GPZL comes in, as a global body. The action planning stage is the critical stage where we need to bring everyone in. In the early stages, we need to get as high as possible within the health sector.
- **Takahiro Nanri:** We have existing resources that we should try to use effectively.

III. Additional Comments

Action items:

- Identify others (like Pat Lammie) with geographic expertise from other countries/regions who we can learn from
 - Pursue existing funding from leprosy community to address concrete goals
 - Further action toward zero discrimination
 - Address the gap between country review and road-mapping process
 - Discuss additional representation from NLPs from different regions
 - Prioritize integration in our messaging to countries
- **Amar Timalisina:** Involvement of organizations of persons affected is also very important.
 - **Arielle Cavaliero:** Resource mobilization is not a question of interest, but governance. This will inform action planning and research.

- **Gangadhar Sunkara:** I'm motivated to be involved in more sub-teams, like seed-funding.
- **Alice Cruz:** The right to health is a government obligation. One way to ensure governments fulfill their obligations is to strengthen local voices of persons affected. They will monitor the governments' actions. Groups of persons affected should not only be consultants but should be strengthened as a group that ensures accountability. There is not sufficient work on zero discrimination. My mandate has three years of work, evidence, and recommendations that I would like to see put into action.
- **Erwin Cooreman:** 1) HQ reports that clofazimine and hydroxychloroquine are potential drugs to treat COVID-19. This could impact leprosy drug supply. 2) The Global Leprosy Strategy will be published within the next two weeks.
- **Benedict Quao:** If we can have a replication of our model in countries which would continue to keep leprosy issues on the table and support the NLPM, it will strengthen our country work. In between the review and mapping, there might be a gap. We need more NLPM representation.
- **Mauricio Nobre:** We have to know we don't have the answers and need to learn from country programmes and patients and use limited resources in the best way to get results.
- **Linda Hummel:** I'm looking forward to practical steps: research workshops, country work, fundraising.
- **Geoff Warne:** 1) Every time we go to a country to talk about leprosy, it will be received as something that's integrated with other NTDs. We will have to think about this with our messaging. 2) ILEP members adopted a statement about engagement of persons affected. 3) ITC has developed a work plan that includes capacity development.
- **Andie Tucker:** David Blok undertook modeling work in 2020. Sundeep has been co-chairing the diagnostic TPP efforts. Both will present during the LRI Spring Meeting.
- **Bill Gallo:** I welcome others to find counterparts to Pat who have other geographical expertise. If we can show real success with our one-time funding, other donors might see the value of investments for quick impact at the country level.

- **Bill Simmons:** Thank you for trusting me as Chair for the next two years. I am looking forward to the next two years as we see more progress as a group and play a role in moving the world toward zero leprosy.