Leadership Team Meeting: COVID-19 Response
21 May 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)
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis Pharmaceutical
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Mathias Duck, Chair of ILEP Panel of Persons Affected by Leprosy
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program
- Marteen Van Cleef, Former Director of Challenge TB project, KNCV (observer)
- Amar Timalsina, President, IDEA Nepal

Secretariat
- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Christine Fenenga, Director of Country Programmes, Global Partnership for Zero Leprosy
- Andie Tucker, Project Manager, 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
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Jan van Berkel, Chair, Executive Group, Leprosy Research Initiative
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
I. Organizational updates on the impact of COVID-19: Bill Simmons

- Process for new secretariat director:
  - We are working with the Task Force for Global Health for a new candidate for Courtenay’s replacement. We have several good candidates and they are being interviewed by staff at the Task Force for Global Health. After that interview process, they’ll move forward 2-4 candidates and a few leadership team members will conduct a series of interviews with the final candidates. Dave Ross and his team will make the final decision, with our input. It’ll be another few weeks before that’s completed. By the end of June an offer will be extended. Once the pool is reduced I’ll share all of the resumes with the entire leadership team, in case there’s any specific input you may have.

- What are you concerned about in the field of leprosy work right now? And longer-term?
  - Mauricio: there’s a very fast-growing curve of new cases. We have about 290,000 total cases and about 20,000 new cases yesterday. We have many political issues around control measures from COVID. In many places people are not respecting lockdown. All health activities are related to COVID and leprosy activities have stopped. Our hospital has reduced the number of days we’re seeing leprosy patients. I’m really worried about the number of new leprosy cases, because in the last two months we’ve seen a dramatic reduction in the amount of new cases of leprosy diagnosed. I am also worried about disabilities. People are afraid to come to the hospital, and the whole health system is being reoriented around COVID-19. I am worried about the impact that will have on leprosy-related disability.

  - Amar: The situation in Nepal Is getting worse. The number of COVID-19 cases is increasing rapidly. We are still under complete lockdown. Persons affected are facing problems because of the two-month long lockdown. Last month, a person affected that’s being treated for reactions came from the western part of Nepal by ambulance to Kathmandu and paid a lot of money to be transported, more money than they could afford. Persons affected are facing problems with wound care management. They are getting ulcers and wounds but are unable to reach the hospital because of the transportation lockdown. There are also basic needs that are going unmet because of the lockdown.

  - Erwin: India is still in lockdown. Case numbers are rapidly increasing. They are slowly relaxing lockdown measures, but this is because of economic needs, instead of as a public health response. Offices and markets are reopening. From next week onwards, they’ll open transport between states again, despite cases going up. The guidelines from WHO HQ have been published. Leprosy is very
hidden, but the guidance is written for all communicable and noncommunicable diseases. The pages we have published on the GPZL website are more illustrative for programmes. If COVID-19 becomes a protracted problem we will have to resume some leprosy activities at some point. We need to start thinking about what these will be and when and how they should resume.

- Taka: Japan is starting to reopen, expect Tokyo, and it will be opened later this month. The foundations’ activities are still suspended. Sadly, our former chairman passed away last week. One of the few activities we’ve still maintained during the lockdown is attempting to extend Alice’s mandate. The Japanese government committed to pushing this forward. We are planning to submit a resolution for the extension of her mandate at the meeting of the Human Rights Council meeting next month. I will share more information about this as it is released by the Japanese government.

- Geoff: We had a meeting of the ILEP CEOs yesterday. We are hearing that ILEP run hospitals are being taken over for COVID-19 response. They’re still trying to run leprosy programmes, but they have issues with trying to keep leprosy patients safe, and keeping leprosy programmes going when hospitals are full of COVID-19 patients. The lockdown situation in the Dominican Republic is affecting staff (health and social services staff) because most staff are over the age of 60, and were required to stay in lockdown, so they can’t carry out their duties. Accessing PPE is still challenging and is in many cases prohibitively expensive. LEPRRA has a lab in South India that is ready to work on COVID testing, but there are delays between the state and central government that has kept the testing from being authorized. A number of ILEP members have begun talking about resumption of activities, about health systems that may have been damaged and what work might need to be done in health systems strengthening. Some ILEP members have seen some advantages to working from home, which I think will prompt ILEP members to take a new direction in work arrangements post COVID-19.

- Arielle: Switzerland is seeing a relaxation in lockdown and people can return to work, but many are staying home still. Work activities at Novartis haven’t slacked much. The engagement we have through Working Group 1 has allowed us to stay engaged and close to the impact of COVID-19 on leprosy.

- José: There are differences between individuals states in the US regarding opening up. We’ve reached a high percentage of unemployment in the US. The hospitals are taking a huge hit because they are not doing elective surgeries and treatments, and some may close entirely. Non-essential staff have been reduced in the hospitals, but essential staff are still working. We’ve started support
groups for our staff at the hospital where I work to support mental health. Persons affected by leprosy in the US are now better able to access clinics and leprosy services are deemed as essential services. On a personal note, I was tested for COVID-19 because I was exposed to someone sick. My test was negative, but I still have to be quarantined for 14 days. The IDEA calls that we host on Fridays are serving as a positive support group for those that are joining. Tomorrow’s call will focus on mental health.

- Bill: Sundeep, our staff member at Cambridge, has found a drug compound that has a good binding capacity to SARS-COVID-2. They are working on it in the lab to see if it might be a candidate in a drug trial. There are many potential candidates, but we are trying to do our part.

- Courtenay: The situation is changing rapidly. We’re starting to understand that this disease will be with us for some time to come. This has implications for the third working group that is planning for the future.

II. Working Group Updates

Working Group 1:
- Our working group had our third meeting this week. We discussed the surveys that have gone out and discussed our analysis approach for that information. The NLPM survey has been closed after a total of 32 responses. The NGO and civil society organization surveys have now gone out and are being disseminated through the ILEP network and through Working Group 2. This survey will be open for responses through next week. We’ve allocated the list of 32 respondent countries to each member of the working group. We’re asking working group members to look at a whole country to make a short report on the main challenges and priorities. Colleagues from Novartis will go through all the data related to supply chain from every country and we will meet next week to share results and talk about follow up with countries. We’ve also discussed as a group the question of who should be responding? We’re talking about leveraging our network of WHO local offices, NGOs, and Novartis local offices in response. We may also provide general guidance with feedback that might be helpful, and will be elevating success stories from particular countries that are managing well. We will compile a full report from our findings.

- Mauricio: Arielle, did you get a response from the Brazilian programme?
- Christine: Yes, we did.
- Arielle: From a geographical standpoint, the NLPMs are often based in the capitol, but the patients and NGOs are spread throughout the country, and are able to offer perspective on health services from a different regional perspective. This has been valuable.
Working Group 2:

- Mathias: Our working group has hosted 6 different calls with more than 25 organizations of persons affected, with 75+ persons affected attending. We are hosting a call with women affected next week. We are seeing a lack of basic needs: needs for food, water, and soap. We are seeing needs for basic medical care: wound care and ulcer management. There are issues of mental well-being and domestic violence. In some places, there are issues with bringing COVID-19 patients into leprosy colonies or health facilities, putting persons affected at risk. Alice is writing a letter to the UN member states and we are producing a report of our current findings.
  - Arielle: To what extent will new partners be brought into the response to this report? Maybe there are opportunities to bring in more diverse partners to meet these needs.
  - Mauricio: Have you been talking with MORHAN? Places that are highly endemic for leprosy are also highly endemic for COVID-19 in Brazil?
    - Mathias: Yes, we have.

Working Group 3:

- Geoff: The group has not met, but we have accumulated people that are interested in joining. We will need to rethink the TOR of this group for the reasons Courtenay described at the beginning of the call. ILEP members are starting to think about the shape of health services post-COVID.
  - Courtenay: I am working on the draft TOR and will be sending it out to WG3 tomorrow.