

Leadership Team Meeting

April 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
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis Pharmaceutical
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- VRR Pemmaraju, Technical Officer, WHO Global Leprosy Programme (observer)
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Alice Cruz, UN Special Rapporteur (observer)
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV (observer)
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- David Blok, Postdoctoral Researcher, Erasmus MC (observer)

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:

- Rekha Shukla, JS, MOH&FW India

- I. **Welcome and update from Leadership Team Chair: Bill Simmons**
- II. **Framing the discussion; Coronavirus potential impacts on leprosy programs: Courtenay Dusenbury**
 - We want to frame the discussion about where we are concern Coronavirus, and then we want to hear from you what you think the impact will be on your organizations and your work. What do you see as risks of the current situation? What are ways the Partnership could work together over the next twelve months to respond. We'd put in place milestones for 2020, but we're now finding that we likely will not be able to travel to achieve our country goals, but some of those milestones need to change in the current climate. What is the most urgent situation facing us, and what should we be doing to harness the power of the Partnership and make sure we're having an impact on those who need our assistance? Usually in similar crisis, like Ebola, the government public health system is likely to fail. Everyone in the system could be called to work on Coronavirus, and some of the standard activities of the public health system, including disease surveillance, diagnosis, treatment, etc., will be sidelined. The people that had been working in small leprosy programmes may be called to different things. This calls into question whether or not MDT is going to be available, whether people will be able to get drugs monthly, whether they'll receive treatment for reactions, and whether or not new cases will be diagnosed. We feel it is important to think about these challenges and the challenges facing persons affected: traveling to receive therapies, increased stigma and discrimination, etc. While these problems are arising, there will likely be an influx of new money into national governments. We have seen a few requests for proposals coming from the US CDC, whose budget has increased substantially over the past two weeks. This type of funding tends to suck the life out of other programs in countries. With these facts in mind we'd like to hear from you on three points: 1. What is the impact on your organization? 2. What do you see as the risks of the current situation? 3. What are ways the Partnership can work together in this new environment?
 - Bart: The national offices of FAIRMED have stopped their long-term projects, or are slowing their work. A risk for the organization is that part of our funding will be delayed, but other funding opportunities are arising. We've switched to emergency mode in most of our countries, except India, meaning that we're working national responders. We see a few opportunities to defend the leprosy agenda: Looking at the supply chain, how can existing patients on medication get access to their MDT, can they collect longer-term medication? We're considering clinical guidelines. There is a good example from Brazil, but what does COVID-19 mean for a person under leprosy treatment. We are concerned about medical

access. In some places, persons affected by leprosy can't go to a regular hospital, so we are trying to counteract that. We're trying to prevent parallel systems. Coronavirus may suck up energy and resources and people, but response to the disease should exist within the health systems, and some of that increased capacity should remain after the crisis. This could be used to talk about universal health coverage. That's another opportunity— to combine coronavirus response and leprosy case finding, for example. I think we should continue to share information together. Yesterday we had a call with ILEP and I was alerted that there might be a credit crunch on African banks. We need to see what the opportunities are— as some of our work slows down there will be other opportunities that present themselves. This will end suddenly, and we should be ready then to pick up where it's stopped.

- Benedict: Ghana is in the intermediate phase. We have over 162 cases, and some parts of the country, around the capitol and the second biggest city, are under lockdown. The National Leprosy Programme (NLP) has already sent drugs to the regional offices for the next six months, so if there are able to deliver it downstream, we shouldn't have a big challenge with drug availability. The challenge will be in areas that are under lockdown. We don't know whether patients will be able to move to get their drugs. However, we are not under full lockdown, people can still go to the hospital, get drugs, and get food. We are hoping we will not have patients missing medication for now. Active campaigns and contact tracing will be reduced, because some of these coordinators will be called upon for COVID-19 response: contact tracing, for example. We have not yet been called to change our activities. Currently, only the departments that work in port health, surveillance, etc., are working on the pandemic. Maybe in a month or two that will change. There's supposed to be a webinar for all African NTD programme managers. After that we'll have a better idea of what's happening all over the African continent.
- Jan: I am reporting for LRI. LRI is in the middle of processing proposals that have been presented for this year's call. We need to prepare ourselves that some of our LRI funders may face income issues, which became clear in the ILEP update yesterday. We expect delays in implementation of research programmes, so we may need to keep funds aside to cope with that. Things like overhead costs, staff costs will continue in many places, while the research may be hampered. There is a lot of uncertainty, but we are aware that some LRI partners have reserves, but some are in precarious situations immediately. The GPZL should continue coordinating meetings. I think the work in preparation of leprosy research proposals can and should continue. Some of our medical advisors have been called by the Ministry of Health to assist with the COVID crisis in their home

country, so they may be less available. The challenge for the GPZL is to prepare for the moment things return to normal. I think this will be phased, and will differ by country. We can prepare scenarios and proposals for appeals to donors to get things reorganized and started again.

- Amar: In Nepal we are under complete lockdown. There are five reported cases in the country. It is good that our government took initiative in the beginning to lock down the whole nation, but people affected by leprosy are often poor, and they did not have time to adequately prepare for the lockdown. They did not have enough time to buy food. We are not allowed to go out, and our government has not provided necessary food. Last week IDEA met on Zoom with representatives from 8 countries to identify challenges presented by the pandemic for persons affected. We identified many similarities between the two diseases: isolation, stigma, and discrimination. These are things persons affected by leprosy already face. Our lock down is scheduled to continue for another 10 days. I think persons affected by leprosy have had access to MDT, but now are facing problems getting to the hospital to receive the medicine and treatment.
- Cairns: I would like to reemphasize what Amar has said. The greatest impact is going to be on people affected by leprosy and their families. This is a group of people that are often poor, vulnerable, and already marginalized. This current crisis may widen inequality in society. I'm not sure what we can do about that as a partnership, but I think it's important that we recognize the difficulties that people affected by leprosy will experience as a result of this crisis.
- Mauricio: In Brazil we now have 5700 cases and 200 deaths. This is a rate of about 3.5%. Our first case was about one month ago. In the last 24 hours we've diagnosed more than 1000 new cases. The leprosy programme has many concerns. We're seeing a high percentage of cases among ages 60+. We think we have about 8000-9000 patients of leprosy in this age group on MDT. There are people that need to go to health units and come back home, often on public transportation. This is a threat to the health of these patients. The programme has decided to deliver drugs to treat leprosy reactions for more than a month at a time. This usually is not done, but we had a national decision from our drug department and for the next three to four months, we are allowed to prescribe reaction medication for three months at a time for patients who are stable. We are trying to deliver MDT for people who are well for two or three months at a time, but we don't have enough MDT. The Ministry of Health has asked WHO to send us more MDT in advance to allow us to deliver MDT to patients for at least two months at a time. We expect to see a reduction in the number of new cases because all activities for active case finding will be stopped, and contact tracing

will be reduced. We expect a reduction on the Q rate and a reduction in the rate of disability evaluations. We may see an increase in Grade 2 disability because there will be a reduction in self-care group meetings. We don't know what the results of the interaction between COVID-19 and leprosy will be on leprosy reactions. It's worrying, because many of the leprosy patients are immunosuppressed, because of prolonged steroid use and because of the rate of elderly persons diagnosed with leprosy. The Brazilian Society of Hansen's Disease published a document with guidelines, but we will have a virtual national meeting with reference doctors to discuss clinical guidelines next week.

- Geoff: My comments mostly come from a meeting yesterday with the ILEP CEOs. Firstly, ILEP members are already seeing reductions in revenue, as much as 40% in some cases, in community fundraising. Government contract income is still stable. The actual effect depends on many factors: how diversified fundraising portfolios are, where they are in their fundraising cycle, etc. Second, programs in the field have largely stopped. Some ILEP members have already made staffing cuts in response to the current situation, and as a preventive measure because of a projected on-going reduction in income. Many ILEP orgs are preparing staff salary cuts or are looking for home country government support to mitigate that need. Almost all orgs are using reserves to maintain liquidity and to continue paying staff salaries. This will delay the hit until 2021, which means that orgs will be more at risk then because of depleted reserves. There is concern about the weakening of health systems, and the role of ILEP members in maintaining infrastructure. Governments are going to need us. ILEP members are already offering governments their human resources and infrastructure, for example, laboratory services, and specialist staff. This is a normal for ILEP members working in countries with emergencies, but this is an abnormally large emergency. Leprosy diagnosis, treatment, and contact tracing are all likely to be stopped, and there is concern about MDT provision. We saw during the Ebola crisis— it had a suppressing effect on treatment for other diseases. There are concerns about the effects of this crisis on the poorest. The economic effects of this crisis, in terms of lives lost, may be as severe as the health effects. We could see widespread suffering and potentially starvation. There are concerns about resources, especially concerns about the failure of banks. ILEP members have monies in banks in the countries where they work. The Partnership can listen to the risks our group is elevating, the opportunities we're identifying. This is not only enlightening, it gives us a chance to respond together. We can support one another in maintenance of basic infrastructure, to try to see how we can together continue to deliver the essentials. We've seen that even in the face of emergencies and wars, somehow, faithful staff have continued to work with

people affected by leprosy. We can encourage governments, WHO, ILEP members and Novartis to be flexible and creative in maintaining MDT supply. We can build interaction with people affected by leprosy, both at the local level and internationally.

- Christian: In Benin we have nine official cases and five municipalities that are labeled 'high risk' and have been isolated from the rest of the country. Schools and universities are closed for two weeks. A coronavirus management center has been set up in the capital city where patient care can be centralized, but most emphasis has been placed on individual preventive actions. The problem here is the capacity of confirmation of cases. Only one laboratory is able to confirm cases at the national level. All leprosy screening campaigns have been stopped. Our priority is the continuity of care: provision of MDT and cortical steroids for patients. We are disseminating information on vulnerable populations, like those with Grade 2 disability. Regarding the Partnership, I think we need to work closely together so we're ready to act when the situation normalizes.
- Mark: The transition to working from home has not been too disruptive for Novartis. Everything that has to do with patients has been disrupted, so that's more of a challenge. We have a lot of production capabilities in India and China, and sourcing key ingredients and manufacturing and shipping have been made more difficult. I would like this group to help me understand, how can we minimize the disruption to patients? The first step is to manage our supplies. It is important for us to continue to supply MDT to the market, and I want to know from the group how we could evolve the model to ensure that patients continue to get their medication. Then there is general concern on our side about this impacting our ability to interact with key stakeholders, in order to ensure that we progress in our common fight against leprosy. I'm also concerned about focus. For Novartis, leprosy is a flagship, so I don't think we will see decreased focus, but I think we need to be mindful. We can make sure we have joint communications to ensure that leprosy stays in the mind of people in the wake of this more urgent health emergency. We can reflect on how we can get those messages across. Just like we can tailor our supply model to the crisis, we can tailor our communication. I am confident that we should be able to maintain the level of activity we had for leprosy throughout the crisis, and find ways to offer emergency support to countries that need it most.
- Arielle: I had a discussion with our Novartis colleagues about MDT production and distribution, and they were able to give positive feedback regarding first mile distribution— from the manufacturing site to the countries. Our site in India, despite losing 40% of its staff to illness, has still be able to manufacture MDT,

which is earmarked as a priority product. There is less visibility on last mile in-country distribution. We will be leaning on the Global Partnership and our colleagues here to get specific feedback on the concerns, so we can connect distribution channels and facilitate solutions. There is a willingness to diagnose in-country supply chain obstacles— this was a priority for Novartis this year, and that has now been accelerated given the current emergency. We should have a follow up discussion to find an effective way to get feedback from countries, be it from the National Programmes themselves, or in-country partners to identify challenges and start to address issues.

- Taka: Our government has not yet issued a lock down of our cities, but our foundation is encouraging our staff to work at home. This is complicated by the fact that we started our fiscal year today, so we have been busy. Our activities have been suspended, but we are not directly operating grassroots projects, so this will have a different impact than other ILEP members suspending their work. Our conferences and planned visits for the Goodwill Ambassador have been suspended. Our funding is stable for this fiscal year, but we do not know about next year. Our funding mostly comes from the Nippon Foundation (NF), and NF's fundraising may be impacted by Coronavirus. I think the Global Partnership can play a role as an information clearing house, communicating the impact of Coronavirus on leprosy. For instance, our foundation has to change our activities for this fiscal year, but before doing so, we need information. A platform like the Partnership can play the role of an information clearing house so everyone can access needed information.
- Alice: This crisis highlights two problems that already exist for persons affected and their families: access, and the underlying social determinates of health. I think it would be important to look at the invisible side of leprosy, and not just MDT supply. Many people suffer from leprosy reactions and they need rehabilitation services, wound care, and they rely on self-care and self-help groups to try to address the mental challenges that come from having leprosy. All of this is jeopardized, not only access to MDT. This is an opportunity to see how we can ensure access to these complementary treatments. It's not easy, but it's important. Another thing to consider is the important role of the state in social protection. I've heard that persons affected are already having difficulty accessing social benefits they rely upon for supporting themselves. I was working with Claudia in Brazil to make an accessible version of the guidelines the Brazilian Society prepared, and we considered including guidance about hygiene, but then we realized that many persons affected do not have access to clean water. This is an opportunity for us to acknowledge these social determinates of health, because they will have an impact on the interaction between leprosy and

COVID-19. I also spoke with Amar about the reliance of persons affected on informal labor markets, and with lock downs, they will not be able to work. Without being able to go out to work or access social benefits, we are talking about matters of survival. Persons affected on the ground are trying to do things, like food distribution. Leprosy colonies and settlements are especially vulnerable because of their deficient infrastructure. We also need to consider elderly populations affected by leprosy. Persons affected of this generation may live with severe physical impairment. I think there are a lot of issues we can and should try to explore. The Global Partnership can help share information between different stakeholders. I think it is important to receive information and to provide information, and from those outside of the Partnership. I hope the Partnership can help to guide persons affected on protecting themselves, and demanding their rights. NLPs will have problems, so it's important to advocate for them not losing the small resources they already have, but it's also important to help persons affected demand their rights. I cannot do much more than connect with people on the ground, but I can prepare a public statement, but I will not do that to make a rhetoric argument. I will do that if I have enough information and if it will help stakeholders in one way or another. I put that instrument I have at your service. It might be important for fundraising: leprosy is already a neglected disease, and a neglected social phenomena, and fundraising will diminish and NLPs will diminish. We can try to work together on a public statement and I would be happy to do that with you.

- Erwin: Most staff are working from home, so things are being interrupted and slowed down. In India about 1700 cases have been identified so far, and this may be the tip of the iceberg, because access to testing is a huge problem. The whole country is under lockdown, but we are seeing internally displaced migrants are feeling the cities in huge numbers, several millions of them. This may be dangerous if they are infected and taking the disease home. These people have essentially lost their jobs and housing and there aren't means of transportation, so they are walking home 500 or 700 kilometers, sometimes. All religious places are closed. These are the places poor people, including persons affected, could get charity and free meals, and now this has stopped. This is a struggle for poor and vulnerable people, but especially persons affected by leprosy. The NTD department at WHO has worked on a guidance document on what activities should be maintained to ensure critical services for NTDs. That document is ready for publication, but it's on hold right now, and we're checking to make sure it's not conflicting with other existing guidance. Tomorrow it will be released, with guidance on how to support each disease as a minimum package. For leprosy the bare minimum is to ensure that patients on treatment can

continue treatment and avoid treatment interruption. We've said we should be flexible: give two or more months of MDT at a time if it's required, continue treatment in home villages if people are leaving referral centers, reaction treatment and nerve function assessment should continue because they prevent future mobility issues. This is harder to do than say. We're still suffering from the stock-out of MDT, which was just being solved. Novartis supplied all their drug of the drug from their facility, but that was based on the previous stock they had, and that's been exhausted. There may be interruption of supply of PB and MB at the moment. The good news is that dapsons production has been restored to Novartis and Novartis is packing MDT again, and we expect that all supplies to countries will continue in April and May. While there may be a higher demand by giving two or three months at once, we may be confronted with challenges in mitigating stock-out at the country or programme level. No travel is taking place, so all global meetings are postponed. Our next meeting was planned for June. It's unlikely to take place as scheduled. We expect that this will be postponed as well. One more note about the NTD package for care, the leprosy community can offer something in response to COVID, in the sense that COVID deals with patients that have been isolated and may be ostracized, so health workers that are used to working with leprosy are familiar with the situation and can share their experience and skills to counsel these kinds of patients. This is a contribution from leprosy work to COVID response.

- Bill: The next phase of the LepVax trial was scheduled to being July 1st in Brazil, and that's now been postponed. There are programmes that are being disrupted that are linked to mass drug administration. We have projects where training for leprosy morbidity is linked to mass drug administration, and as those campaigns are paused, the training programmes are paused as well. There's redeployment of workforce toward Coronavirus. There are partners whose medical staff are being allocated, or beds of hospitals are being requisitioned for COVID-19 work. We have done something similar with Dr. Sandeep in the UK with deploying our resources to molecular drug discovery for COVID-19, away from therapeutic discovery for leprosy. We are seeing the beginning of these disruptions.
- José: IDEA international realized that social distancing was going to have an impact on our brothers and sisters around the world, so we initiated an international call to a number of IDEA chapters, and we're going to continue that conversation this coming Friday with more chapters. I have seen the fear that is perpetuated from the fear of the unknown, and the ultimate separation of families. Even though people can communicate with their family members, they can't travel to go see loved ones who may be ill. On our IDEA call we talked about the issue of medication access, and we shared concerns about access for

people in places where MDT is given out at general health centers that may be closed because of the pandemic. We're also concerned about the fact that this isolation can make family members, especially women, more vulnerable to domestic or intimate partner violence. Everyone on the call shared that they were following government guidelines on social distancing, but everyone expressed concern for what might happen in the future. On Friday I hope to have more information about what's happening in country. We are concerned about what might happen to the mental health of individuals going through this. We've already experienced isolation as persons affected, so we have something to teach in this time. We want to stay positive and continue to provide emotional support to our colleagues in other parts of the world.

III Response from the Secretariat: Courtenay Dusenbury

- I tried to categorize what everyone has said into a few function groups. Overall, I think that the Partnership can be sharing information between stakeholders. We can consider doing those on the website, or we can consider establishing discussion groups or helping with existing groups. Something that seems urgent and necessary is clinical guidelines. The Partnership can take the documents coming from WHO and Brazil and coalesce them on our website to make them available to everyone. Second term, we heard that there's a need to further explore the situation with patients, regarding MDT availability, wound care, and other treatment issues. Perhaps we can consider establishing a task team or an emergency working group of interested organizations to work in that area. Then there's the issues related to persons affected: helping to amplify their voices, building interaction and connectivity between existing organizations, and trying to bring attention to that harsh reality these folks are facing. The next area I identified is funding: we need to be very careful about stewarding our 2020 resources wisely. Some ILEP members may not be able to contribute to the Partnership next year, and we need to be saving resources this year to the extent we can. Finally, what I heard was the importance of a post-COVID strategy for countries: beginning to think now about the situation in countries and the nature of our work in response. There will be leprosy cases growing in the absence of surveillance activities, so how will we be helpful to countries in that new dynamic, and how will that influence our overall milestones? I suggest that the secretariat takes this information from today and comes back to you with a broad new strategy for the next 8-12 months, and get some feedback on that so we can move forward together on this revised strategy. I want to invite David and Maarten to offer feedback.
 - David: My work has shifted to investigating the impact of COVID-19 on other NTDs. There was a question raised by the Gates Foundation towards the NTD modeling consortium, to investigate what the potential impact would be of postponing or stopping MDA for one or two years for several NTDs, and thinking

of catching-up strategies. This is in line with what we've just discussed about our thinking about post-COVID strategies for leprosy. This kind of analysis is now taking place within the NTD community: to give an indication of what could happen in terms of impact on the incidence or prevalence of the disease, and how can we catch up afterwards.

- Maarten: It's clear that in some countries the impact is enormous and that the impact in other countries may be enormous, but we don't know because of lack of capacity to test, etc. I'm considering three different issues: clinical impact, health service delivery impact, managerial impact (NLPMs, what it means for them to operate). I think we should prepare for the worst in each country— total lockdown. I considered the Stop TB partnership to think about what GPZL can do, and they've already compiled a list of guidance about what to do for countries in the case of TB and COVID. Similarly, the Partnership should show global leadership by creating generic guidance on the website that can be translated and implemented at the country level. As partners, we can help to translate generic guidance into national guidance— each country will be different from another, but we as partners can help them to make generic guidelines into national guidelines and then help with implementation.
- Bill: We will look forward to the secretariat reporting back to us on their recommendations and ways forward.

IV Secretariat Director Position Description Process: Courtenay Dusenbury

- I've been called to another assignment at the Task Force for Global Health. This assignment is linked to funding— we anticipate large amounts of US funding and international funding to go into COVID-19 response, and the Task Force is interested in seeing how we can bridge the gap between COVID-19 emergency funding and NTDs. We are going to be launching an advocacy effort to connect NTD programmes with basic health services strengthening through COVID-19 in the hopes that we can bring new resources to NTDs. I will be transitioning to that role over the summer. We would like to post my position and go through a process of interviewing candidates. We don't know how long it will take, but we hope to find someone by August. We are planning to take the job description and post it within the Emory University system by mid-April. Emory will select the top 10 candidates. We will review them internally, then select the top three or five candidates, then we would like the leadership team to interact with those candidates in some way. I would appreciate it if some of you would volunteer to be in a working group that could help us to look at the resumes and qualifications of the top candidates and then develop and process for interaction with those candidates.

- Bill: I think instead of talking about that right now, I ask you who are interested in participating in the review process and design email Courtenay and copy me, and we'll form a committee.

V. Updates and Observations from Leadership Team Members

- Jan: I am wondering if we should consider having more frequent calls right now, if there are reasons to do so. I would welcome another meeting two weeks from now. This is a powerful means of communication and interaction.
 - Bill: I agree. There's a lot of valuable information represented by this group, and I know we're all engaged in different activities, but I hope that you all will share as much information as possible through the secretariat so we all can benefit from the collective power of our work together.