

## Leadership Team Meeting

January 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
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- VRR Pemmaraju, Technical Officer, WHO Global Leprosy Programme (observer)
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Arielle Cavaliero, Program Manager, Novartis Foundation

#### Secretariat

- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Christine Fenenga, Operational Excellence Coordinator, Global Partnership for Zero Leprosy
- Andie Tucker, Communications Specialist, Global Partnership for Zero Leprosy
- Cassandra Holloway, Program Support Specialist, Global Partnership for Zero Leprosy

#### Invited but unable to attend

- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme (observer)
- Mark Alexandre Rogers, Novartis Pharmaceutical (observer)
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Alice Cruz, UN Special Rapporteur (observer)

**I. Welcome from Leadership Team Chair: Bill Simmons****II. Discussion on US Funding/Hansen's Disease Program: José Ramirez**

- Background on this topic: in the US there was a national leprosarium from the 20s until the 90s when President Clinton signed an executive order saying that no new patients would be admitted and 10 clinics would be established. The program in Baton Rouge had a clinical branch and a research branch. During the last funding cycle there were efforts to cut the budget by 50%, which meant cutting back on outpatient services and staff. That cut was not made, but now there are rumors that there are efforts to cut 20 positions from the research and clinical branch, and reduce the size of the clinic. This will mean new patients diagnosed might not be able to receive services, and will contribute to the growth of stigma. The board of The Star is communicating with the clinic to better understand the impact this will have, and we're communicating this impact to congress through our congressional delegation. The ultimate consequences will be the reduction of services for those that have experienced the disease, but also a loss of credibility and international leadership in research.
- Courtenay: We share the concerns of José. US donor agencies have never included funding for Hansen's Disease in their portfolios. They fund other Neglected Tropical Diseases (NTDs), but leprosy has never been included in the US AID portfolio. We've had discussions at the Task Force and with the Leadership Team about getting more engaged in advocacy efforts to ensure there's appropriate funding for research and treatment. We're going to travel to Washington in early February to meet with lobbying firms to potentially help us engage a strategy. This would be the Task Force's strategy for NTDs, but we would include leprosy as a part of that. We think this is an opportunity to contribute advocacy to help ensure the funding we need is available for this year.
- José: The board members of The Star are collecting data to draft an article to publish on World Leprosy Day on this topic. I'm willing to contribute to the US AID lobbying effort.

**III Communications update: Andie Tucker**

- World Leprosy Day is coming up at the end of the month and we're working on our online campaign for that day. World Leprosy Day, in addition to being an advocacy day for leprosy, is also our organizational birthday, so I am making a video to our members to celebrate our successes and thank them for their contributions to the partnership in the last two years. I ask that you would distribute this video to your staff within your organizations, because this work would not have been possible without them. I'll send the video to you the week before World Leprosy Day. We're also working on our World NTD plans with other NTD groups at the Task Force for Global Health. We will be hosting

an event targeting our local Atlanta-area community, and leprosy will be one of the NTDs highlighted at the event. A livestream of this event will be available online.

#### **IV Research Agenda Manuscript Update: Cairns Smith**

- The research agenda was fully published last September in Leprosy Review and we sent it to The Lancet. They've sent that out for review and we are waiting for the editors' feedback. An important priority is to work out how we will move this agenda forward. The research agenda was a shopping list and we need to focus this down. The workshop in Amsterdam helped do this. The critical thing now is to identify the leadership that will take this forward.
- Geoff: A research coordinator isn't in the budget, so I'm wondering how we move the agenda forward without someone in that role. How do you see this working best?
- Cairns: I think this will be difficult to move forward and bring different groups together. I'm not sure who will carry this forward.
- Jan: We've stressed the need to find additional capacity. LRI is happy to contribute as much as we can, but our primary function is to fund research. This needs more attention when we talk about the work plan.
- Bill: It is not primarily a budget question. The first question to be answered what this person would be doing, who would they coordinate, and what the expected outcome of the role would be. Would they coordinate working groups, or actually write grants, and for whom? We have to answer clearly what we want someone to do, what that work would look like, and then we can see what it would cost. Should we make a task force to explore this further?
- Cairns: Individuals will work in their areas of expertise, but we need to move that to a higher level. We need people working on mapping linked to people working on early case detection. I think it's a facilitation role. I think these are coordination issues not dependent on funding.
- Jan: Can Cairns and I work on this and report back to the Leadership Team at the next meeting?
- Bill: Does anyone else want to participate?
- Arielle: I would also like to participate.
- Bill: Thanks to the group of three.
- Pemmaraju: Maybe it's time for us to discuss with the national governments if they can take in some of the research agenda, in India and in other countries.
- Jan: Maybe we will get in touch with you to further elaborate on this, Pemmaraju.

#### **V. Country Work Updates: Christine Fenenga**

- We submitted the country reports to Nepal and Morocco in November. We haven't received a response from them yet. Both of the National Leprosy Programme managers from Nepal and Morocco have been transferred, but we're still trying to keep in contact through others in the ministry. This has confirmed what we know to be true about working with government programs: there will be challenges (delays, transfers, etc). Although the National Leprosy Programme Managers (NLMPs) are important we also have seen critical limitations (transfers, often position low in the hierarchy). Dr. Rabindra, the NLMP, has reached out to the NGO partners, advising them to keep the 'not yet' approved roadmap and review report as guiding documents in their planning for 2020. Next week at the workshop several people from Nepal and Morocco will be in attendance, so we will have a meeting with them, and the likely successor of the NLMP of Morocco, who participated in the review will attend the workshop. I'll be visiting Nepal again this year to help to develop the roadmap and implementation plan, but not until the government approves the country report. We've received official requests from a number of countries that would like to work with us next year. Those on this list of official requests now are: Angola, Madagascar, Côte d'Ivoire and Nigeria. Discussion during next week's workshop will lead to the official criteria for selection for future country work. We are still getting new best practices in, so that's on-going work. Lately we've reviewed and prepared 10-12 best practices, and there are others in the pipeline. GPZL communications and Infolep are working to link their sites to increase traffic and the impact of scientific content on both sites. At the end of last year, we began a discussion about how to reorganize the operational excellence group, but we will further develop this at the meeting in Amsterdam next week.

#### VI. **Resource Mobilization and Partnerships Update: Courtenay Dusenbury**

- Julie Jacobson is in Atlanta today to talk about the advocacy and resource mobilization plan. Once we finalize our ideas we'll send it out and talk about it in February call. We had a meeting with the CEO of Glide Foundation. They have a focus on diabetes and malaria, not leprosy right now, but they're willing to consider our work and a partnership with us. Their budget is 20 million a year, they've just started and are deciding how they're contributing, but they're interested in convening groups. We suggested a meeting to talk about our approach, and to get feedback from other groups that have worked in a similar way. Julie and I are talking about other ideas that might be opportunities to follow up over the next year. Simon Bland, who worked at DIFID and US AID, gave us good advice on the leprosy partnership. He thinks we're on the right track and is excited to see the work we're doing in leprosy.
- For the past 2 years we had conversations with the NTD support center about Leprosy (the organization is based here at the Task Force for Global Health). They're putting out call for research proposals on leprosy today. We were able to suggest ideas about what leprosy topics should be included. Ninke and Cairns contributed to this, and most of

their contributions have been included in the call for proposal. The next step is to have the call for proposals and for us to help researchers apply for these opportunities. These are yearlong engagements with a cap of about \$300,000. In addition to the NTD Support Center call, we're looking at the research priority list and discussing with Julie to see where we might be able to shop these ideas.

- Geoff: What is happening with MacArthur? And it seems in the work plan that the intention is to continue with Julie until July, but what happens after July?
- Courtenay: The MacArthur proposal is being reviewed by technical experts and we'll know in early February if we've been selected as part of the top 100. Julie's time is limited with us, and our goal is to develop this fundraising capacity on our own. She's helping us to develop key targets, but we should now be taking the step to represent ourselves with most donors.

#### **VII. Partnership Implementation Meeting in Amsterdam: Bill Simmons**

- One of the objectives of the meetings is to better understand how we make the determination about the criteria used to select the 5 countries to work with in 2020. How are we going to decide what countries fit into the work plan from our perspective? How do we address that there are some countries that can never be ignored? How do we manage that the partnership could never take on all the work of the countries of India by ourselves, but can contribute? What are the strategic reasons and the actual process for selecting five countries? How do we make good decisions about where and how we engage countries, especially in low endemic states that can quickly lose personnel?
- Courtenay: The goals for this meeting are to develop criteria for selecting and ranking the countries. Another goal is to have an open conversation about what partnership is going to mean. A country-based partnership, in support of the ministry of health, bringing together all of these partners around a shared goal. This will be the first time that this happens. We really want to have a flexible, dynamic, and engaging conversation about what this means for organizations, individuals, and for the Global Partnership as a whole. We are thankful to Katy Pountney at Novartis, who volunteered to help us with this effort. She's a very good facilitator that's using some interesting techniques to bring people and groups together to form teams. We're really looking forward to this discussion. It will give us a good model for moving forward that can then be further discussed by the leadership team, we can seek validation from others who were not at the meeting, and we can use it as the basis for our work this year.
- Bill: At the end of the day, our goal with the workplan is to be successful in doing this in five countries, and that's not going to be free of charge, and it's going to require human and financial resource to make that happen effectively. We're getting serious now about actually accomplishing some of the goals we've set out for ourselves as a partnership.

- This is a big part of getting more serious. Now's the time to roll up our sleeves and put our concepts into practice. Questions?
- Geoff: You've mentioned five countries, but it's important to talk about the fact that we're looking from 2020-2003 so we're getting into that middle phase of the action plan, which includes another 15 countries. The 5 is only the starting point. It's easy to get fixed on that 5, but it's a much bigger picture that we've got to grapple with. Courtenay, do we have a final program?
  - Courtenay: Yes, we'll send it out.
  - Arielle: One question I had is specific— are there any pre-reads that are included for the group? The second is, do you have an idea in mind of whether this will be a one-off workshop, or a part of a series of meeting where the outputs will need to be further defined with the same group of participants or different participants, as we think about what 2020 holds for us?
  - Courtenay: The meeting materials, including the video, were sent out yesterday. Let me check to make sure everyone received that. As far as the future of the group, we are hoping that one thing that will come out of the meeting is a conviction about how we're going to work together in the future, be it a working group of various organizations, country specific working-groups, and whether they'll need to meet regularly, and how. This will all be part of the discussion next week.

#### **VIII. Work Plan and Budget Update: Courtenay Dusenbury**

- Let me say briefly about staff, as we know, Jessica has left to pursue her career in the arts and Cassandra, who has been working on our budget, has been promoted to another assignment. We currently have two of us at the Secretariat, me and Andie, and Christine in Amsterdam. We have two interns this semester, both public health students. One is focusing on communications and one has just started working on programs. We're going to be recruiting a communications person soon, and a part time budget person. Please bear with us as the team is quite small at the moment. Moving forward to the workplan: in putting together the workplan and the three budgets this year we faced an interesting challenge. For the first time we needed to think about the process that we're using to develop these budgets. In the past we'd only had one budget that was partially funded by ILEP and partially funded by Novartis, but thanks to the generosity of the Sasakawa Health Foundation we now have an additional \$450,000 a year, and we needed to figure out how to fund specific activities across three budgets. One thing that has become clear is that we need a better process. The process we have right now is that we are coming up with the individual budgets based on what the donors have told us they are interested in, or their financial limitations. We are negotiating those with the three donors and then we will be bringing them to the leadership team for discussion. One thing that has becoming apparent is that there's a

lot of interest in how the Sasakawa funds should be spent. There were many suggestions, including the one Jan raised about hiring new staff, doing an economic analysis, funding research projects, etc. These suggestions are all very good ones, but we need to have a way for the leadership team to look at funding decisions across budgets and to allow the donors to make their imprint on the funding that they are giving. We discussed this with the leadership team at the Task Force for Global Health, and we would like to step back and put in place a better procedure for governing the funding of the Global Partnership. We're suggesting to hire a consultant with \$25,000 in funding from the Merck corporation received via the Task Force to hire a consultant who can come in and work with us to develop a better governance platform for funding. This person will take a look at where the funding is coming from, how we're currently making decisions, how we can open up both the budget decision making process and the process of deciding where we're soliciting funding. They will help us in defining our values around where we're spending money and how we're allocating it. There are a lot of questions that are very complex that a lot of organizations have gone through, and we're now in a position of going through the same questions. We suggest that we hire this consultant and begin bringing her on board to talk with the Leadership Team and the secretariat about a new governance structure.

- Jan: I welcome the investment in this next stage of the partnership. We may need an appropriate way of governing our decisions and priorities, so I welcome this opportunity, and I am glad to hear that this capacity will be made available through an experienced consultant from the Task Force.
- Bill: Courtenay, what's the timeline on that?
- Courtenay: I think we want to try to get her in next week. For this year, the budget for Novartis and the budget for ILEP are probably non-controversial and can move forward. The real issue for us to consider this year is the addition of the Sasakawa funding and how we allocate that. That budget year cycle begins in April, so we can take a month or two to figure out our process. Then we can use that process when we meet in March in London to take a look at that money and discuss how the Leadership Team thinks that money should be allocated.
- Taka: Courtenay, I support your suggestion.
- Courtenay: From the perspective of the secretariat, these are growing pains, but I am excited about this. It's wonderful to be in a position where we have so many good ideas on the table and a strong leadership team to be able to engage them.
- Geoff: I also support what Courtenay is doing in this regard, and I think it's very nice that there's a funded consultant available to do this work. I've been uncomfortable with the budget process this year for some similar reasons to what Courtenay said, and in my

mind, we've got to get away from the three budgets idea. We need to move toward a model where the leadership team is taking a leading role in thinking through what the funding priorities should be. One of the leadership team's primary roles is strategic priority setting. I think that the donor organizations would pay careful attention to what the leadership team was saying about how their resources ought to be used. I think this is a great next step for us.

**IX. Closing Remarks from Leadership Team Members: Bill Simmons**

- Pemmaraju: I would like to update everyone on two things: WHO is organizing an informal consultation for defining criteria to declare elimination of transmission of leprosy from the 12-14 February in Mexico. We would welcome your ideas on that discussion. The other update is that the guidance on the treatment of reactions has been completed. Before we finalize it we'd like to circulate it to leaders of the membership team so we can get feedback on it. Dr. Paul Saunderson has been working on it, and it will be ready by the end of this month.
- Jan: We are getting more and more feedback that finding necessary amounts of Rifampicin for PEP implementation is becoming a challenge. I'll be ready to talk about this in the meeting next week.
- Geoff: Looking forward to the meeting that Dr. Pemmaraju spoke about earlier, where the results of the National Leprosy Programme evaluation are going to be presented. There will be a few of us there. I've taken the opportunity to spend a day with the leaders of the ILEP India offices— most ILEP members are involved in India— so there are about 10 people that will be present. That will be a good opportunity for us to get our heads around how ILEP could contribute more usefully to the emerging priorities for the National Leprosy Programme in India.
- Benedict: It is great to see that we are making so much progress. I wasn't able to represent the Leadership Team in Kenya because we weren't able to get a side session at the 1st International Conference on NTDs in Africa so we made decision to not go. I have to seek approval for all travel outside the country and if it wasn't going to be high-yield it was better to hold on. Next week promises to be good.
- Taka: Alice Cruz will visit Japan in February. I spoke with her yesterday and we are planning to use her visit to Japan as an opportunity to convince the government to extend her mandate. At the meeting in Amsterdam next week I am interested to hear about how the partnership is thinking about the extension of Alice's mandate. Secondly, right after the meeting in Amsterdam I am going to Geneva to meet with Japanese permanent mission to talk about Alice's visit. I'm also going to meet with Dr. Tedros, director general of the WHO. I'm planning to deliver a message from Mr. Sasakawa. Mr. Sasakawa wants to invite Dr. Tedros to the Brazilian National Hansen's Disease Meeting

- in March. I can take this opportunity to introduce the partnership. If you have any ideas of ways I can address the partnership in this meeting, please let me know.
- Mauricio: I would like to share that our National Program is organizing a meeting about Hansen's Disease control in Brazil from 19-20 March. This will be a political meeting. It was planned during Mr. Sasakawa's meeting with the Brazilian president. I will be in Brasilia next week to meet with the National Program and I will try to ensure that the partnership will be discussed in that meeting, and I will try to find a time on the agenda for a presentation.
  - Bill: One of the representations we do not have on the leadership team is someone from a public health institute in an endemic country. I had the opportunity to spend time with Dr. Milton Moraes from Fiocruz. I'd wondered if we should consider public health institute representation from Brazil and perhaps India, at the leadership team level, but I wonder what Mauricio's thoughts would be on adding someone like Milton to the leadership team. Would that be redundant, or would that be advantageous, from your perspective?
  - Mauricio: I think it would be nice. Milton is involved with research and he leads one of our reference centers. He could help to bring together the five reference centers to discuss strategies for research and leprosy control. I think it's a good idea.
  - José: I look forward to the resurrection of the Hansen's disease program in the US, and I want to wish everyone a happy world leprosy day, since we're not going to meet until next month. Two gentlemen who spent a lifetime at a sanitarium in Japan have been selected as runners for the Olympic torch during the opening of the Olympics. We are very proud of that.