

## Leadership Team Meeting Teleconference

6 February 2019

### Participants

#### Leadership team members and guests

- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen (Facilitator)
- Jan van Berkel, President, International Federation of Anti-Leprosy Associations, (ILEP)
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Fareed Mirza, Head of Healthcare Outcomes and Research, Novartis Foundation (Chair, Research Agenda working group)
- Mauricio Lisboa Nobre, Technical Advisor, The Brazilian Leprosy Program, General Coordination of Leprosy and Diseases in Elimination (CGHDE)
- José Ramirez, Board Member, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Bart Vander Plaetse, Head of Programme Unit, FAIRMED (Chair, Operational Excellence working group)
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)

#### Secretariat

- Courtenay Dusenbury, Secretariat Director
- Christine Fenenga, Operational Excellence Coordinator
- Jessica Cook, Communications Director
- Leslie Chananhouse, Operations

#### Invited but unable to attend

- Bill Simmons (Leadership Team Chair), President & CEO, American Leprosy Missions
- David Addiss, Senior Advisor, Secretariat
- Alice Cruz, UN Special Rapporteur (observer)
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Taye Letta, Leprosy Prevention and Control Manager, Ministry of Health, Ethiopia
- Takahiro Nanri, Executive Director, Sasakawa Memorial Health Foundation

### **I. Welcome by Cairns Smith**

Bill Simmons was unable to attend today's call, and Cairns Smith acted as facilitator. Cairns opened the meeting, saying he was inspired by the progress of the partnership.

### **II. Secretariat Update (Courtenay Dusenbury and Jessica Cook)**

#### **Elections (Courtenay Dusenbury)**

According to the charter, four positions are up for reelection, including the chair and country positions. The three current country positions include Mauricio Lisboa Nobre (Brazil), Taye Letta (Ethiopia), and Anil Kumar (India). Taye Letta is unable to continue on the leadership team due to other commitments.

Courtenay asks if the team would be supportive with continuing with Bill Simmons as chair and Mauricio Nobre and Anil Kumar in their current positions. Cairns proposed that it would be useful to reappoint the three people for continuity and support. Several others on the team, including Jan, José, Arielle and Erwin supported this.

For the open country position, Courtenay has received nominations from several African countries, including the Central African Republic, Senegal, Cameroon, Uganda and Lesotho. Being only one vacant position, Courtenay suggested that some of the programme managers from these countries be deputized for other roles in the partnership, if possible.

Arielle comments that the partnership communicate the process that we're undertaking for these positions.

In addition, Courtenay and Cairns suggested that the charter and election procedures be reviewed and revised during the leadership team meeting in March.

#### **Communications and membership update (Jessica Cook)**

The WHO 2030 target survey was sent to all newsletter subscribers last week and a reminder will be today. Jessica encouraged the leadership team to complete the survey and forward to others.

#### *Comments:*

Cairns saw the survey as a positive step for gathering feedback. Erwin thanked the secretariat and leadership team for the survey. He also mentioned that the survey is just one step in the process of gathering feedback. In the coming months, there will be different opportunities to seek inputs, including from global training for NLP managers (April).

A new staff member is joining the secretariat team on 18 February. She will support the many operational tasks involved in communications and membership. Jessica will also begin working on an updated communications strategy and new messaging for 2019 and beyond.

The partnership currently has 425 members (401 individuals, 24 organizations).

### **III. Strategic Outline**

Courtenay stated a few themes for 2019 and beyond:

- Clearly define our goals into an achievable 10-year framework. Our action framework is a start. Now, with new WHO 2030 targets and our key products in development (research agenda, country capacity building model) we can come to agreement on the specifics. We can start working on a 10-year framework, 5-year plan, and an annual work plan.
- Parallel to this, is the need for a visionary group of advisors – some working in leprosy and some without – to help us implement advocacy and resource mobilization efforts. We will put together an advisory group for resource mobilization efforts.
- We also want to begin benchmarking with similar programs so that partners understand the timeframe, commitment and hard work needed to move forward. Guinea Worm, Trachoma and others are partnerships lasting more than a decade. We will hear from these partnerships starting during the March meeting and throughout the year we will have a focus on governance, strategic planning and sustainability.
- The strategic outline includes four components, including:
  - Advance, in the scientific and fundraising arenas, the critical activities needed to accelerate progress on the GPZL Research Agenda.
  - Support national programmes in their efforts to strengthen national capacity and innovation to lead to zero leprosy.
  - Strong and targeted communications to support activities leading to zero leprosy including a robust network, technical tools, advocacy, partnership, policy and resource mobilization.
  - Foster an aligned, robust partnership advocating for increased global and national action and resource mobilization for leprosy.

Courtenay will present the advocacy and resource mobilization plan in March. And, the secretariat will begin forming groups for these efforts.

Jan offers to connect Courtenay with the ILEP fundraising group. Several leadership team members commented positively about the strategic outline and asked if they could share it. Courtenay said an updated version would be available next week for sharing.

### **III. Research Agenda Working Group (Fareed Mirza, Jessica Cook)**

Fareed said he is working on a manuscript for publication. He also shared the abstract for the International Leprosy Congress and says it represents the first alignment of the leprosy community.

He says validation is important before posting the research agenda and he urges caution in posting it prematurely on zeroleprosy.org. Fareed also said a recent Devex article on a key component of the research agenda (post-exposure prophylaxis) shows the need for validation.

Jessica presents the communication plan, which outlines the three products associated with the research agenda: (1) Article in a peer-reviewed journal; (2) Sub-group reports on zeroleprosy.org; and (3) A visual and

concise summary written in plain language. It is intended for a broader audience, including persons affected by leprosy. It will also be part of an advocacy package for making the case for investing in leprosy research.

She mentions that the sub-group reports will be reviewed and validated by the sub-group facilitators before posting on zeroleprosy.org.

*Discussion:*

- Regarding the Devex article, Jan comments that both positive and negative feedback is expected to come. We should anticipate for this and already prepare key messages specially to address any criticism.
- Cairns says persons affected will be most important—a powerful argument for the research agenda will be to hear how these tools have worked for people.
- José comments that it's important to have the voice of persons affected. Medicine impacts persons affected and we cannot have the research without making a connection to the human.
- Geoff asks for clarification on the timing. His understanding is that sub-groups reports should be reviewed by sub-groups, but could be published on zeroleprosy.org prior to the article.
- Fareed says he and the team can work together to have some content on the website.
- Christine asks what journal he is submitting the manuscript to. Fareed says that they're formatting the article for a PLOS-NTD journal.

#### **IV. Operational Excellence working group (Christine Fenenga, Bart Vander Platse)**

*Group conference calls and assignment for best practice documentation*

All 11 groups have been formed and announced on the website. Groups will focus first on collecting and documenting best practices on their specific themes. In an online steering team meeting 17th January the format for best practices were agreed. The format has two components A: a short summary format for first round proposals for best practices, which then few can be selected from for writing B. format for a full best practice.

All groups except 1 (3B) have set a date for their first meeting.

*Toolkit and Help Desk*

We are looking for solutions for the toolkit which are effective and efficient, including using the same platform space as InfoLep and InfoNTD. For the Help Desk, the groups will identify experts suitable to offer technical assistance. This pool of experts can also be tapped from for country reviews.

*Country reviews and roadmap planning*

Progress has been made in the development of the tool we will use for country reviews and development of Country Leprosy Roadmaps. Christine was in Delhi, working closely with Dr. Cooreman and Dr. Pemmaraju of WHO's Global Leprosy Programme on this tool. She also liaised with the WHO SEARO Regional NTD Advisor Dr. Jamsheed Mohamed and had regular contact with Joanne Pritchard of the Uniting to Combat NTD in Atlanta because part of the developed country review tool comprises of the NTD Action Framework.

The tool is now in its draft form and will be reviewed by a few people of WHO, Global Partnership for Zero Leprosy (GPZL) and ILEP before piloting. Christine and Bart are in discussion with the WHO and ILEP about the countries where to conduct a country review and roadmap planning is next.

Christine met with Mr. Sasakawa and his team in Delhi. They were there in relation with a Global Appeal organized by the Sasakawa Memorial Health Foundation and the Chamber of Commerce International. Christine had the opportunity to brief on the developments of the GPZL and lobby for support of the work we do.

#### *Technical Advisory Team*

On 24th of January an online meeting with the Technical Advisory Team took place, discussing the Terms of Reference and expectations of members. It was agreed that the TA team will support the working group based on needs.

Bart commented on the progress of this group. He said national programme managers are not just involved, but have taken charge. The joint country reviews are very encouraging.

Cairns agrees that including the programme managers is an achievement.

Arielle asks if there are targeted countries yet for the peer-to-peer assessments. Christine replies that Nepal is showing interest at this time.

Erwin comments that India is likely to call for a mid-term review of its current five-year plan, which will feed into the next plan period. This may happen in the second or third quarter. WHO has received requests for country monitoring missions to Tanzania, Côte d'Ivoire, Egypt, Indonesia.

#### **V. Updates from Leadership Team**

- Christian: Preparations for the International Leprosy Congress are underway. He is planning sessions for the research group and the operational excellence group.
- Geoff: He had a conversation with Dr. Mwelecele Ntuli Malecela, the new Director of the WHO Department of Control of Neglected Tropical Diseases. He briefed her on leprosy and the partnership. He described a few topics from the conversation, including: 1. She is trying to foster horizontal linkages across NTD community. 2. She strongly said "one size does not fit all" with countries. 3. She hopes to link leprosy with other skin NTD groups. 4. Her passion is on the individual person affected.
- Mauricio: Different political moment in Brazil, some uncertainties for the national program, but he hopes to help the partnership. He thanks the leadership team for supporting his position again.
- Erwin: The earlier planned mid-term review of the Global Leprosy Strategy will not take place as a stand-alone activity. Instead, uptake of the strategy will be reviewed during country missions and other means. The NTD Department is also working on a post-2020 successor strategy for its Roadmap. Being part of the NTD portfolio, leprosy will be included. A separate global leprosy strategy is not per se required. However, it is desirable to have one for the sake of visibility. We must make sure though that the post-2020 global leprosy strategy and NTD strategy are not contradictory.
- Fareed and Bart both commented that they were inspired by the progression of the partnership.

- José: Don't forget the human element, especially for any presentations planned for the ILC.
- Courtenay quotes Virginia Sarah, Immediate Past President of the International Committee for Trachoma Control, who noted that after 14 years the ICTC has grown from a "coalition of partners working in trachoma to THE global program to eliminate trachoma." This is an aspirational goal for the GPZL.

**Secretariat Next Steps**

- The strategic outline will be sent to the leadership team next week for sharing with others.