ILEP Members’ Assembly
Greenville, 20th March 2019

Annex 6 – Members’ Assembly minutes

Expected outcome of session:
Approval of minutes from Members’ Assembly meeting on 10.10.2018
1. Welcome and introductions

JvB welcomed everyone and expressed appreciation for Members’ trust in the Board. He emphasized the uniqueness and vital role of ILEP as a group of organizations standing together in the field with one another, with government and with persons affected.

1.1 Appointment of President and Board members

GW summarized the nomination process and said that JvB (for President) and AJ and BS (for the Board) were the only nominees. The MA confirmed these appointments.

GW explained the error by which BM and BK had moved into new terms of service in 2017 without an election. The MA confirmed these appointments with effect from 2017.

1.2 Update from the Board

BS gave an update from the Board. Most of the Board’s recent activity was related to Tanya’s departure, GW’s appointment and the budget. He acknowledged weaknesses in process and communication between the Board and MA while recruiting for Tanya’s replacement, but said this was due to time constraints and with the aim of allowing for a good handover period between the outgoing and income CEOs.
2. Reports and Updates

2.1 Panel of women and men affected by leprosy
MD reported that the Panel had good discussions between themselves and with the ITC. The Participation policy for ILEP was under consultation with the wider community of people affected and was not yet ready to be presented to the MA.

*Heads up:* The Panel was exploring the possibility of a common ILEP project for inclusion and participation, working with the ITC and GPZL’s Operational Excellence Working Group.

*Recommendation:* The Panel asked ILEP Members to support the mandate of Alice Cruz (UN Special Rapporteur) especially in connection with country visits. She plans a meeting of persons affected at the Human Rights Council in Geneva in June 2019. The ILEP Office is supporting the coordination of both actions among ILEP Members.

*Reminder:* The Panel reminded Members of ILEP policy on language and communication. Some posts on social media are not in line with the policy and CEOs were asked to remind their communications teams and their partners of the policy.

2.2 ILEP Technical Commission
PS reported on the previous day’s meeting.

*Workplan:* There had been some frustration that ITC had no clear linkage or influence on the GPZL Operational Excellence working group, and it wanted this to be clarified. ITC now proposed a workplan mainly focused on the development and revision of guidelines and training materials which could feed into the eventual Operational Excellence Toolkit. Dr Pemmaraju had been present at the meeting and there was a good cooperative atmosphere with WHO GLP.

*Research:* ITC does not oversee research, but individual members are involved in several projects and it maintained an overview. PS mentioned exciting research developments at the moment, including PEP and AIM projects.

*Data and reporting:* ITC supported the position that ILEP should work to ensure high quality WHO data from countries, and encourage WHO to expand its data elements, rather than collect parallel data. Where WHO is restricted in what it can publish or where there are gaps in reporting, ILEP may continue to gather fuller, independent data and consider publishing where this was justified.

2.3 Country Coordination
AJ reminded the Members to share examples of good practice and coordination with the ILEP Office to be posted on ILEP’s website, as agreed at the previous MA.
MR (Senegal) and BM (Nepal) summarized the previous day’s coordination meetings. Key lessons included that transparency, good communication and sharing of information are essential for working and moving forward together speaking with one voice. Next steps included working with government and other stakeholders, as a national partnership for zero leprosy, to develop a joint national plan tackling key issues at national level. BM emphasized that Head Offices have an important role in fostering collaboration including country plans and joint funding applications.

AJ shared his reflections on the coordination meetings. The exchange of information had been essential, and the meetings had shown how active collaboration improves effectiveness, reduces duplication and boosts the health information system. He noted the need to work on mid-term and long-term plans with local partners. It was agreed that the meetings should continue with the following countries in 2019:

- March 2019: Brazil (to be confirmed) and Ethiopia
- October 2019: Niger and Bangladesh

PD commented that effect:hope, while not ILEP coordinator, plays a significant role as funder in countries such as Bangladesh. It was agreed that any Member actively involved, either through its own in-country programs or as a funder of projects implemented by others, should participate in these coordination meetings.

PS noted that the 4 out of 22 high endemic countries that do not have an ILEP coordinator provide poor quality data to WHO. He asked if ILEP can engage in these countries to help improve the reporting. GW added that the withdrawal of ILEP coordinators also removes much of the potential driving force for GPZL.

**Action: GW to form a small group and discuss possible solutions for coordination when there is no active ILEP member**

3. **Global Partnership for Zero Leprosy**

JvB welcomed Courtenay Dusenbury (CD) and Christine Fenenga (CF) to the meeting for this item. CD thanked the ILEP Members for their support and spoke on the achievements during GPZL’s first 7 months, the timeline or action framework, and the overview business plan and budget for 2019-20. She emphasized key success factors for global health partnerships learned from her experience with IANPHI: confidence of donors, mutual trust between members, hard work over several years, ability to demonstrate added value, common sense, courage and belief in the face of doubters, and love, which was so often a driving force for involvement in public health. She reported that as a result of Secretariat advocacy, USAID and the Gates Foundation had both agreed to re-include leprosy within the criteria for funding calls.

CF followed up with a presentation on the Operational Excellence Working Group. There were discussions around the need for active involvement by National Program Managers in
the Operational Excellence design and process. CD responded by describing the engagement already with the three NPMs on the GPZL Leadership Team and her intention to present the preliminary model at this month’s meeting of SEARO NPMs and request feedback.

Some CEOs spoke of feeling disengaged even as GPZL forges ahead. A number of actions for better Member engagement were discussed including:

- ILEP Members to join as GPZL members directly
- All ILEP CEOs to receive the GPZL update bulletins
- More regular communication from the ILEP office regarding GPZL
- Member inclusion through direct engagement in the forthcoming open calls
- Proactive requests for direct ILEP Member input on topics as they arise

**Action: ILEP Office to facilitate the above actions**

CD and CF left the meeting at this point.

JvB asked each Member to confirm its commitment to GPZL and willingness to contribute towards its 2019 budget.

- ALM: Confirmed commitment and will contribute USD50,000
- DFB: Confirmed commitment and will contribute EUR15,000
- SLC: Confirmed commitment and will contribute up to USD50,000
- Fontilles: JA will discuss with the Fontilles board and respond by 30 November
- Lepra: Confirmed commitment through staff engagement but no financial contribution
- AIFO: Budget restrictions but will discuss to make token contribution
- SMHF: TN will discuss with the SMHF board and respond by 31 October
- FRF: Confirmed commitment and will contribute EUR20,000
- FAIRMED: Confirmed commitment through staff engagement and a symbolic contribution of CHF5,000 - 10,000
- DAHW: SK will follow up with Burkard Kőmm
- TLMI: Confirmed commitment and will contribute USD50,000
- EH: Confirmed commitment and will contribute EUR20,000 if concerns regarding inclusion are addressed
- NLR: Confirmed commitment and will contribute USD50,000

4. ILEP for the future

There was an open discussion on GW’s strategic options paper.

4.1 Options for a lower-cost ILEP

Discussion centered around the following topics.
a. The move to Geneva had not yet produced the expected benefits in terms of WHO engagement, but GW expected to report further in March 2019 after renewed approaches to WHO and the UN.
b. Relocation was seen as a 5-year scenario and not a current priority. Savings in early years would be offset by relocation costs and the impact of the loss of good staff. Because of GLP, Delhi could be considered as another possible location beside the ones mentioned by GW.
c. Housing the ILEP office within one Member association might be associated with perceived loss of independence, though this had not been true of LRI or Infolep. The office could remain autonomous if staff are based in multiple locations.
d. Interest was expressed in the ICTC model, under which ILEP would cease to be a legal entity and staff and running costs would be provided by Members. However, doubts were raised whether Members have staff capacity to take on the roles of the ILEP office.
e. Other alternatives to relocation included (a) reduction of CEO role again to 60% as from 2020 or (b) 10% increase in Member contributions from 2020.
f. Expanding the remit of ILEP as a possible vehicle for other NTDs might help with funding but at a cost of loss of focus.
g. If the MA is very clear on ILEP’s primary purpose and value to the Members, the question of how it should function might become clearer.

4.2 GPZL scenarios and what they could mean for ILEP
Members noted the scenarios and their implications. It should be clear by the end of 2019 whether GPZL is successful, based mainly on its ability to secure donors and funds, though it was agreed that we should not too narrowly define ‘success.’ There was discussion on the potential role of the Task Force for Global Health as a credible prime recipient of major funds, coordinating a consortium of ILEP and Government agencies as implementers. It was agreed that at this stage we should not close any door to the possible shape of future large-scale donor funding.

Action: GW to bring further recommendations to the MA in March 2019, taking into account this discussion and developments in the next 6 months, with a particular focus on ILEP’s primary purpose and value to the Members and the implications for structure and location.

5. Approval of Previous Minutes

The Minutes from the meeting held in Colchester on 20 March 2018 were approved.

6. Actions from previous meetings

GW sought Member feedback on a number of questions raised in the Action Point Register. It was agreed:
a. The Working Group on WHO’s proposal to separate rehabilitation from other CBR (Mar 2017/3) is no longer a priority.
b. The framework for a coordinated program to strengthen Members’ collective impact towards zero discrimination (Mar 2017/3) is replaced by the proposed common ILEP project being developed by the Panel.
c. The case for support (Sep 2017) is now picked up by GPZL.
d. The LRI branding (Sep 2017) is resolved by its branding as an ILEP initiative.
e. Employment of Mathias Duck as consultant (Mar 2018/3). Some Members expressed concerns with the current arrangement due to lack of clarity as to whether he is paid as consultant or as representative or chair of the Panel.

**Action:** The Board to review the situation and suggest a solution.

f. Set of basic principles for a stronger ILEP to ensure a strong NGO voice with improved coordination (Mar 2018/5).

**Action:** GW to follow this up with Burkard Kömm and GP.

7. **CEO report**

The report was noted. In response to specific questions raised by GW, it was agreed:

a. The CEO needs to express ILEP’s position within the reality that ILEP is not fully united in its support of the WHO Guidelines.
b. The CEO should present, at the March MA, proposals for an ILEP Conference in September/October 2019. CEOs would then make a decision on whether to proceed with a Conference.
c. The CEO should continue dialogue with Alice Cruz and draw Members’ attention to specific requests.
d. The IDEA strategy should be referred to the Panel for any recommendations.

**Action:** GW to follow up the above actions and consider combining the October 2019 meetings with the ILC in Manila.

8. **Code of conduct/Safeguarding**

The suggested ways ahead in the CEO’s paper were discussed. It was agreed that ILEP does not itself need to take a position on safeguarding: the ILEP office’s role is to facilitate mutual support and sharing of information.

**Action:** GW to approach all Member CEOs and offer to share information and to link those looking to develop codes and policies with those who have them.
9. **Constitution and Bye Laws**

Members agree to adopt the proposed revisions of the Constitution and Bye-laws

*Action: GW to share the final versions with the Members*

10. **Finances**

10.1. **2018 financial update**

Members noted the current situation and the estimates to December 2018.

10.2. **2019 budget**

The Members approved the 2019 budget, with the budgeted deficit of CHF66,905 funded from the General Reserve. It was noted that, if this budget was repeated in 2020, a 10% increase in Member contributions would be needed. This would be discussed in March 2019.

10.3. **Members’ formal commitment to funding the 2019 budget**

The CEOs or Member representatives were asked to individually confirm their commitment to contributing the entire amount of their share of the approved 2019 budget. ALM, DFB, SLC, Fontilles, Lepra, AIFO, SMHF, FRF, FAIRMED, TLM, E:H and NLR confirmed their commitment. SK was unable to confirm on behalf of DAHW, and GW was asked to secure Burkard’s commitment.

10.4. **Reserves**

Members approved:

a. The proposed reserves policy
b. The consolidation of the two reserves from the sale of the building, currently amounting to CHF125,000 and approximately CHF310,000, into a Projects Reserve of around CHF435,000.

10.5. **Appointment of auditor**

The Members approved Audex as the auditor for 2018, and noted that the ILEP office is looking into options for 2019 auditors.

11. **Date and location of next meetings**

March 2019: Greenville, South Carolina, hosted by American Leprosy Missions

- Monday 18th – Country Coordination meetings
- Tuesday 19th – ILEP CEOs meeting, Panel meeting and ITC meeting
- Wednesday 20th – ILEP Members’ Assembly

There would be engagement with the GPZL Secretariat, and the GPZL Leadership Team would meet on the following days.
October 2019: It was agreed that the week beginning Monday 7th should be blocked out for now, and the exact dates and location will be approved in March 2019.

12. AOB

JA informed Members that Fontilles is changing from an Association to a Foundation.

AJ informed Members that DFB is in the process of setting up an international prize for leprosy, to raise awareness.

There was no further business and the Chairman closed the meeting with thanks to the Secretariat for their excellent preparations and to all those present for their participation.