Members Assembly Minutes  
Tuesday 20 March 2018, Colchester

Present:
- AIFO – Antonio Giovanni Farris (AGF)
- ALM – Bill Simmons (BS)
- DAHW – Burkard Kömm (BK)
- DFB – Alex Jaucot (AJ)
- effect:hope – Peter Derrick (PD)
- FAIRMED – René Stäheli (RS)
- FRF – Michel Recipon (MR)
- Fontilles – José Manuel Amoros (JMA)
- Lepra – Geoff Prescott (GP)
- NLR – Jan van Berkel (JvB) ILEP President
- SLC – Maryse Legault (ML) (Skype)
- SMHF – Takahiro Nanri (TN) (Afternoon)
- TLMI – Pete Garrat (PG)

Observers:
- FRF – Bertrand Cauchoirx
- Effect:hope – Deb Hopper
- Panel of People Affected – Mathias Duck (MD)
- ITC – Paul Saunderson (PS)
- Special Rapporteur – Alice Cruz

ILEP Office:
- Tanya Wood (TW)
- Rosa Argent (RA)
- Pim Kuipers (PK)
- Monty Mokhayer (MM)
- Danielle Katsman (DK)

1. Welcome and introductions

It was noted that ALRA has terminated their ILEP Membership and that the Board will contact them about consequences. The Members agreed that they will formally commit to paying their share of the following year’s budget at each October Member Assembly.

- Approval of Minutes: Minutes from the Meeting of the Members’ Assembly held in Wurzburg on 20 October were approved.
- Update from the board was given by BS.
- Sharing of Membership Updates

GP provided an overview and update of Lepra’s activities. There followed discussions on safeguarding in light of recent aid sector scandals. Each member discussed how their organisation or country is addressing this, considering issues such as code of conduct and safeguarding policies.

It was agreed that the Members should continue to share what they are doing in this area.
Action: TW, GP and BK will take this forward and share codes of conduct with members, with a possible reference to the Core Humanitarian Standards.

- Introduction to Special Rapporteur

AC gave a summary of her three year mandate. She explained that there are 3 levels of action (international, national and local) and that she will be focusing mostly on the national level. She will also work on the international level but the local level is where she needs ILEP’s cooperation, with access to information and knowledge of the ground.

AC will produce a report for the Human Rights Council based on official country visits. She will prioritize endemic countries, her goal is to include the issue of leprosy among migrant and refugee populations.

2. ITC and Panel reports and updates

Panel update (MD)

MD provided an update on the Panel’s discussions and activities. This included:

- The Panel will collaborate with the ITC in order to update the stigma guidelines.
- MD suggested the possibility of developing an ILEP policy regarding the participation of persons affected.

ACTION: The results from the ILEP survey on participation will be recirculated and MD will present his recommendations on a new ILEP policy regarding participation of persons affected at the next meeting.

ITC update (PS)

PS provided an update on the ITC’s discussions and activities. This included:

- Participation – An update on the Temporary Expert Group on participation. The stigma guidelines will be updated with some funding from NLR, but additional support will be needed from other ILEP Members.
- WHO Update – WHO now has an online portal for submitting data. Countries can upload their data and manage it online. There is hope that this will make the WHO data more complete and accessible in future.
- M and E and indicators – WHO have developed their indicators related to the data that will be uploaded on their system. ILEP M and E group are working on basic indicators that it will use, ITC will discuss and make comments over next few months.
- Statistics and ILEP position statement – The list of statistics used by ILEP will also be worked on by ITC members over next few months to ensure consistent and accurate communications across the federation.
- Concerns about and benefits of chemoprophylaxis were discussed.

PS noted that ITC & LRI are well-functioning working groups in areas of leprosy control and research and need to be considered in forming the GPZL working groups and highlighted the need to avoid duplication.

LRI update (JvB)

JvB provided an update on the LRI and mentioned that it is now in its 5th year and invited all ILEP Members to join as associate members. A joint call with EDCTP was successful and
raised another 4.5 million for leprosy related research in Africa. ILEP Members were invited to attend the LRI spring meeting (5-6 April).

3. ILEP 2017 reports

- ToR chair of Panel:

The proposed ToR was discussed and reflected upon by the Members. They shared mixed views on the remuneration of the chair, impact it may have on the other Panel members and the independence of the Panel if the chair is paid by ILEP. It was agreed that it is better to employ Mathias Duck as a consultant to coordinate the panel rather than him being paid for a voluntary chair role.

The Members voted on ILEP employing Mathias as a consultant Panel coordinator, rather than as chair. He would however retain the Chair position and the situation will be reviewed at the October meeting.

This was approved by a vote of eight in favour, two against and one abstention.

- CEO 6 month report (TW and PK)

An update was given by TW on the ILEP office.

- 2017 Annual report (RA and PK)

The ILEP annual report 2017 was discussed. The annual report was an opportunity to show how ILEP is working towards its strategy. Question remains on how can we evolve the data we collect? It was noted that the report reflects the ILEP indicators from the strategy but these will be reviewed by M&E group.

The ILEP Annual report 2017 was approved by the Members.

- 2017 Finance report (BK)

BK presented the 2017 audited finance report. It was mentioned that the 2017 overspend was mainly due to Ordre de Malte refusing to pay the remaining amount of their Membership contribution and additional unexpected costs including a consultant for the CEO summit.

The audited financial report was approved.

4. Country Collaboration

AJ presented an overview of where we are to date, and plans for moving ahead. It was mentioned that coordination is the core of ILEP and that we need to improve our data on the website and interactive map.

It was also noted that collaboration strategies must primarily focus on and be owned by stakeholders at the country level. It was suggested that there should be an extra half day at each MA meeting to discuss 2 countries.

It was decided that Members will review their data on the ILEP website and map before 30th of June, point out any discrepancies and send the required updates to the ILEP office so they can update the website. It was also noted that Members should share examples of good practice by 31st of August from which some will be selected and posted on the website.
The proposal to improve in country collaboration will be further discussed at the October Members Assembly.

5. Global Partnership for Zero Leprosy and implications for ILEP

TW gave an overview of the current status of the Parnership. There were extensive discussions around what GPZL means for ILEP. Members shared their thoughts and concerns. It was noted that they recognized the potential of the initiative but were concerned about duplication.

Some Members believed that the potential benefit to access new institutional funds and taking the research agenda forward outweighed cost. Others raised concerns that there were still many unknowns with the Partnership, that we need to be cautious as to where the funds were coming from.

There was an argument for a stronger ILEP to ensure a strong NGO voice, with improved coordination. A draft of basic principles for ILEP will be taken up by TW, GP and BK.

It was agreed that the Members will be informed more frequently after GPZL leadership team meetings about the outcomes and proceedings of the Partnership.

It will be proposed to the GPZL to include ILA in the Leadership team.

Budget: The draft Partnership budget for the first year was presented. So far ILEP has pledged 200K USD (with another 100K to be used for a coordinator position for Working Group 2 – Operational Effectiveness) and Novartis 342K USD. It was made clear that ILEP does not support first or business class travels, expensive hotels or per diems.

6. ILEP looking ahead to 2018 – ILEP Plan and Budget

TW presented a scenario paper for discussion. Members opted for the second option which would mean that the ILEP office would cut its technical advisor role. TW noted that as an outcome of no longer having an ILEP technical coordinator would require membership commitment to fullfill these roles.

ACTION: TW to circulate a request for membership support to cover the absence of the ILEP technical coordinator role.

2018 budget: The Members voted on the two proposed budget options from March to December 2018. Option 2 (smaller budget for ILEP based on reduction of technical officer) was approved with 7 votes. Option 1, or retaining technical role, but covering the increase through ILEP’s reserves, received 3 votes.

7. AOB & close

- Members agreed that it was not a good use of resources for national country coordinators to attend the MA, since it is only a governance and administrative meeting.

- DFB have offered to host the October ILEP meetings with the dates TBC.

- Meeting closed