ILEP Members’ Assembly
Colchester, 20th March 2018

Annex: 1 – Members Assembly minutes, 20.10.2017

Expected outcome of the session:
Approval of minutes from Members Assembly meeting on 20.10.2017
Members Assembly Minutes  
Friday 20 October, 2017 Wurzburg

Present:
AIFO - Antonio Giovanni Farris (AGF)  
ALM – Bill Simmons (BS)  
ALRA - Matthias Wittrock (MW)  
DAHW - Burkard Kömm (BK)  
DFB - Alex Jaucot (AJ)  
Effect:hope - Peter Derrick (PD)  
FAIRMED - René Stäheli (RS)  
Fontilles - José Manuel Amoros (JMA)  
NLR - Jan van Berkel (JvB) ILEP President  
SLC - Maryse Legault (ML)  
SMHF - Takahiro Nanri (TN)  
TLMI - Brent Morgan (BM)

Apologies:
Lepra – Geoff Prescott (GP)  
FRF – Michel Recipon (MR)

Observers:
FRF - Laure-Emmanuelle Payre (LP) & Bertrand Cauchoux (BC)  
ALM - Darren Schaup (DS)  
Mathias Duck (Panel of Women and Men Affected by Leprosy, MD)  
Wim van Brakel (ITC Panel chair, WvB)

ILEP Office:
Tanya Wood (TW)  
Monty Mokhayer (MM)  
Rosa Argent (RA)  
Nathalie Bonvin (NB)  
Pim Kuipers (PK)

1. Welcome from the Chair

Approval of Minutes: Minutes from the Meeting of the Members’ Assembly held in Amsterdam on 10 March were approved.

It was noted that discussions relating to changes in the constitution will be carried over to an appropriate time.

2. Sharing of members’ updates

The CEOs of two ILEP members (DAHW and FAIRMED) provided an overview of their organisations. This is part of a new standing agenda item, agreed at the London CEO summit in September and proved very welcome addition to the MA agenda.

3. Reports and Update

3.1. CEO report (TW)

- Considerable changes to ILEP team including new staff and the office move.
Recent focuses for the secretariat have been the CEO summit, the NNN conference in Dakar, the social inclusion framework for the annual conference in preparation for the conference Germany and the global partnership with the broader leprosy community.

Country coordination and determining what we mean by this is a continued challenge. AJ thanked for his leadership role.

Reporting and data collection. The team has pulled together ILEP data for the London Declaration 5th report scorecard. There is a need for clarity with the leprosy community on key targets and how we track those.

Policy and advocacy. Identified the huge potential to work better together as ILEP through the triple zero campaign framework. It was noted that TW takes on the role of Chair of the NNN and that links with Uniting to Combat should be maximised over the next 12 months.

Comments from the members:

- Two issues (1) reporting and data collection will become increasingly difficult, (2) happy to see strategic discussion around world leprosy day and believes strategic communications at policy level is appropriate for ILEP's communication function (MW)
- Consider building a business case focusing on 50 million people at risk of leprosy (rather than reported cases). DAHW has existing relationship with new WHO Secretary General. (BK)
- Institutional fundraising. RA, with backing from BS, will establish a new institutional fundraising network meeting via bimonthly regular calls, to share knowledge and potentially coordinate approaches where possible. (BS)
- Members must engage and take collective ownership. (JvB)

3.2. Panel of People Affected Update (MD)

Reflected on two questions to help define strategy and priority – (1) what should an advisory panel do to be functional and effective, and (2) how can we be a better voice of the people affected by leprosy?

MD reported back with 3 priority recommendations:

1. Participation and empowerment – research to determine what meaningful and impactful participation and empowerment of people affected involves; create local advisory panels of people affected; organise national workshops about stigma and discrimination; engage people affected to propose research topics and to be research partners.
2. Communication with and among affected people – translate important and relevant documents and information into local languages; develop mechanisms or platforms for communication
3. Knowledge of situation and voice of people affected by leprosy, especially on women and children – Mapping concerns

MD’s added a personal recommendation to establish an English scholarship for leaders or people with potential of leadership, especially women.

Comments from the members:
• Important to have the voice of people affected. If we want to leave no one behind we need to include older people – not just women and children. (RS)
• Could the country workshops support the wider NTD community? (PD)

3.3. ITC Update and Research Champion update (WvB)

Reflection on the structure and the role of ITC, noting (1) ILEP needs clarity on current research priorities; (2) the importance for ILEP to understand what is happening regarding research across the Federation; (3) the need for better translation of research findings into policies, practical tools and practices.

Proposal for a revamped ITC would involve stabilising working groups linked to the Triple Zero strategy.
  ▪ Zero transmission. Diagnostic test development; indicators, mapping and data quality; prevention and early detection of leprosy;
  ▪ Zero disability. Diagnosis management of reactions and NFI; self-management and cross-NED self-care;
  ▪ Zero discrimination. Participation of affected persons; repealing discriminatory laws and policies; revision of the ILEP guidelines to reduce stigma

The new structure would widen scope, strengthen link between ITC and field programme, strengthen capacity of ITC to tackle work, allow involvement of affected persons. Some disruptive innovations were also identified.

Comments from the members:

• 4 issues to address: (1) alignment of ITC with ILEP strategic priorities; (2) strengthening the link between ITC and field programmes; (3) communication to members from ITC; (4) how can we more effectively align the priorities of ILEP and LRI. (BM)
• Constraints relating to the renewal of ITC members. (AJ)

3.4. Country Coordination Champion (AJ)

Explored interest in coordination, noting this will be a long road. There is a need for discussion at three levels – (1) where there are multiple ILEP members (2) where there is only one ILEP member, and (3) where there are no ILEP members (or ILEP members are withdrawing). There is also a need to think beyond leprosy to include coordination among organisations working in the area of NTDs.

ACTION: AJ will make a proposal for the ILEP members Assembly in March 2018.

4. ILEP going forward

The minutes of the CEO Summit were read. No comments.

4.1. Discussion of organisational structures (TW)

There is a spectrum of possibilities for the structure of ILEP - from forming a single entity to a loose civil society network.

It was agreed that we see ourselves most closely as a consortium. It was questioned whether we are just a leprosy consortium. It was noted that it is not incompatible for ILEP to
have a leprosy-only focus, even if members have a broader focus. There is a need for the consortium to grapple with the rapidly changing realities & context.

Members Feedback:

- ILEP needs to dramatically expand its membership at national and sub-national levels. There is a strong need to increase (PD).
- ILEP members have discretionary capacity for funding allocation that is not necessarily the case for others - such as NTD NGOs. If we added these, it would make for a very different dynamic (BS).
- Our strength is our networking capacity (MW).
- What about going for collaborative funding? We will bring our institutional fundraisers together. BS will initiate (BS).

**ACTION:** TW, BS, JV, GP and PD will continue to work on a proposal for discussion at the March Member’s Assembly.

4.2. **The Global Partnership for Zero Leprosy**

JvB summarised history (Beijing meeting, steering group, engagement of The Taskforce for Global Health, survey, agreement to proceed). Context is good for developing partnerships,

The Partnership would focus on 3 key areas through developing working groups:

1. Research – defining the gaps
2. Programme Excellence
3. Fundraising and Advocacy

There is a need for resources if we are to bring this further. The ILEP secretariat can contribute. The Partnership needs a secretariat and resources. We need to give this a chance, and prioritise fundraising. One of the main reasons to have a global Partnership is that we cannot currently show that things are changing (improving). We don't have a compelling story. We need to get things coordinated, demonstrate the impact

**Resolution proposed by BM** – ILEP is committed to exploring the viability of the Partnership. Out of the 11 members in the room, ten voted in agreement with this motion (with one abstention)

Members agreed that TW will continue to engage in the Partnership negotiations. That TW will be able to allocate ILEP time and resources to the Partnership. That TW will make ILEP members aware of emerging needs in the Partnership development process and negotiations.

5. **Plan and Budget 2018 for ILEP**

Meeting continued in closed format (Members only).

The members accepted unanimously to maintain Tanya Wood at 60% of her time.

The Members Assembly accepted unanimously the Budget proposed for January till March 2018.

4. **AOB**

None, and meeting closed.