Members Assembly Minutes
Friday 10 March 2017, Amsterdam

Present:  
AIFO - Enrico Pupulin (EP) & Antonio Giovanni Farris (AGF)  
ALM - Jim Oehrig (JO)  
ALRA - Olaf Hirschmann (OH)  
DAHW - Burkard Kömm (BK)  
DFB - Alex Jaucot (AJ)  
Effect:hope - Peter Derrick (PD)  
FAIRMED - Rene Staeheli (RS)  
Fontilles - José Amoros (JA)  
FRF - Michel Récipon (MR) & Grégoire Detoeuf (GD)  
Lepra – Paul Watson (PW)  
NLR - Jan van Berkel (JVB) ILEP President & Chair  
SLC - Maryse Legault (ML) (Skype)  
SMHF - Edward Vela (EV)  
TLM - Brent Morgan (BM)

Absent: Ordre de Malte

Observers: Mathias Duck (Panel of Women and Men Affected by Leprosy)  
Paul Saunderson (ILEP Technical Commission)

ILEP Office: Tanya Wood (TW)  
Pim Kuipers (PK)  
Monty Mokhayer (MM)  
Sean Mowbray (SM)  
Alecia Rokes (SR)  
Anna van ’t Noordende (AVN)

1. Welcome from the Chair

Approval of last minutes: The Minutes from the Meeting of the Members’ Assembly held in Bern, Switzerland on 14 October 2016 were approved.

2. ILEP Members Update

- Lepra – Geoff Prescott is the successor of Sarah Nancollas as CEO of Lepra.  
- SMHF – Mr Sasakawa visited India earlier this year for World Leprosy Day. He plans to visit Indonesia 6 times in coming years. The next visit to Indonesia is set for 12-16 April 2017. We would appreciate it if ILEP members could utilize the visits as effective advocacy opportunities. Also 282 new cases in the Nepal districts of Banke and Bardia were reported during Dr Kita’s visit to Nepal in February 2017.
TLMI – TLM India has appointed a new CEO, Mary Verghese, (the first female CEO of TLMI). Amar Timilsina from ILEP’s Panel of People Affected is on TLMI’s international board. TLM India released a short documentary ‘the Unwanted’, an educational piece now on the website.

NLR – NLR won the Dutch Postcode Lottery ‘Dream Fund’: a € 9.3 million project on prophylaxis called PEP++. Duration of the project is 5 years.

3. ILEP Office Report

Highlights from the ILEP Office report included:

- **Advisory Boards**: A new ITC and Panel have been appointed and met on Thursday 9 March; their work plans will be presented later.
- **Membership**: Despite the work on alternatives, it was decided that the old fee structure will continue. Further work is needed on the Membership Strategy and the group who volunteered for this will start the discussion on this. CIOMAL and Anesvad are still potential ILEP Members, who will need following up.
- **Office move**: ILEP is looking at other office space as need to move from IAS by September.
- **Annual report**: The ILEP Annual Narrative and Finance Report 2016 has been produced and shared with members.
- **Website**: The website is re-aligned with the Triple Zero Campaign. ILEP wants to include more stories and engagement of members on the website. The intranet is work in progress, most resources have been uploaded.
- **Country level strategies**: Communication with countries needs to be improved and requesting members support with this. A Country Coordinator Terms of Reference (ToR) has been developed.
- **Office staffing**: A new Communications Coordinator has been appointed (Sean Mowbray). The CEO vacancy will be discussed later.
- **Triple Zero Campaign**: The Triple Zero projects discussion papers have been developed and will be discussed later.
- **NNN**: The ILEP CEO currently spending 30% of her time on NNN / NTD Summit.

**Annual 2016 Report**

**Reviewing Progress against the Strategic Goals** - The 2016 Annual narrative and financial report has been shared with the members. There is a need to improve the data collection to measure progress on the Strategic Goal indicators. This will need to be reviewed for the 2016 Report. ITC members have agreed to review the indicators and look at improving the data collection.

**Measuring the Enabling Actions** - The ‘who what where’ map is on the website and the information added to NTD Partners Map. Members will be requested for updated information for this, as well as a Membership survey in third quarter of 2016.
For future Annual Reports it would be good to have more input from the Federation and to get more key data and stories on specific topics.

Financial report

BK presented the financial report. All ILEP assets are now in one account in Switzerland.

The 2016 report is overspent due to higher than anticipated audit and accounting costs. In 2016 there were additional costs for three audits, rather than one due to two UK audits and one Swiss one. ILEP is looking into the possibility of lowering accounting and audit costs in 2017. The financial report was approved by the members.

4. Moving Ahead on Triple 0 Campaign

Zero Transmission:

- **ILEP**: The Global Partnership for Zero Transmission Steering Committee held its first meeting in February 2016, hosted by the Novartis Foundation in Bern. The Task Force for Global Health will follow up with a stakeholder analysis to look at what the potential for this Partnership is. It is hoped the partnership will be launched in the third quarter of 2017.
- **Panel**: ILEP's Panel of People Affected has two new members: Paula Soares Brandão (Brazil) and Amar Timilsina (Nepal). The Panel stressed the importance of the participation of people affected on every level and of working in a sensitive manner. The Panel supports Zero Transmission but stresses that this should not be to the exclusion of other areas (disability & discrimination).
- **ITC**: The ITC identified a number of projects across transmission, and assigned individuals to specific projects. The ITC will focus on diagnostics; diagnostics in relation to other NTD; chemoprophylaxis and case finding; immunoprophylaxis/vaccines; a commentary on the WHO WER; and drug treatment and resistance. The ITC will also focus on more accessible communications. Editorials for Leprosy Review can be used to communicate outcomes of ITC and Panel projects.

The MA proposed to have half a day at the October meetings devoted to presenting ‘disruptive innovations’ for transmission.

Zero Disabilities

- **ILEP**: There is a push within the WHO to make rehabilitation the focus of the WHO, and other aspects of CBR to be the responsibility of other IGOs. ILEP suggests a working group to discuss these issues, focusing on leprosy only at this stage, to work towards reporting to the WHO’s disability & rehabilitation team and advising ILEP and the membership on this shift. Will report back to the MA. The working group will be short-term, approximately six months.
**ACTION:** PK to put out call for people to engage in working group. TLMI & GLRA volunteer already.

- **Panel:** The Panel stressed the importance of reaching the local level and would like to focus on self-care groups. The Panel thinks that we may need new innovations in the field of disabilities.

- **ITC:** The ITC will focus on helping patients be more aware of developing reactions and nerve function impairments, and on post-MTD surveillance. The ITC and the Panel will discuss how to motivate people during and after treatment. One ITC member will discuss the production of Prednipsacks with a company in India.

**Zero Discrimination**

- **ILEP:** Suggestion to the MA is to develop one coordinated programme to strengthen the collective impact of the members to achieve 0 discrimination. This is valuable to ILEP to achieve greater impact and where other organisations are looking at ILEP to take leadership in this. This would be a coordinated programme with coordinated plans, possible coordination resources, and creating strong partnerships with others. A number of Members expressed their support for helping develop this framework.

- **Panel:** The Panel feels most strongly about this issue. Participation of and capacity building among people affected by leprosy is important. Human rights training and using schools and children to raise awareness. The Panel will work alongside the ITC on participation with Michael Chen (TEG) and revising the stigma guidelines. Could possibly work with IDEA.

**ACTION:** ILEP Office to upload database of people affected organisations onto the website.

- **ITC:** The ITC will collaborate more closely with the Panel. Two main areas of work: continuation of Temporary Expert Group on participation and revision of stigma guidelines and advocacy toolkit.

**5. External Initiatives**

**Global Partnership Update:** The Steering Committee met in February. A stakeholder analysis will be conducted by the Task Force for Global Health soon (most likely disseminated by ILEP) that will lead to an action-oriented agenda that will be shared with ILEP members. The partnership will help ILEP mobilise resources and commitments.

**NNN & NTD Summit:** The NNN has a new operating framework (‘BEST’: Behaviour Environment Social inclusion & Treatment) that will be formally endorsed at the NTD Summit. The NNN will open up its (free) membership, ILEP members will be approached to sign up individually as NNN member. The ILEP Communications Coordinator will spend 10-20% of his time up to the Summit to update the NNN website. ILEP hopes all members are attending the NTD Summit.
9. Internal Issues

CEO recruitment: The proposed job description for the CEO was shared. It has been recommended looking for someone strong in advocacy and with a public health background. TW also indicated that it was important in considering a new CEO appointment to use the opportunity to reflect on the amount of engagement between ILEP members and the ILEP Office.

A special meeting will be held after the NTD Summit or at another suitable date to discuss the vacancy and recruitment process.

The MA agreed to move forward with recruitment. The recruitment committee will be: Maryse Legault, Jan van Berkel, Bill Simmons & Brent Morgan. The MA will be asked to approve the new CEO appointment.

**ACTION:** ILEP will follow up on setting the timing for the special meeting of CEOs.

Bye laws: The amended Bye Laws were approved. Some changes noted that will also need updating in the constitution at a later date.

Country Coordinator ToR: It should be added that ILEP Country Representatives should engage in wider forums, beyond leprosy. The ToR was approved with amendment.

**ACTION:** Members agreed to work with their staff to remind them of the commitment to country strategies.

Gender survey: ILEP’s survey on gender indicated that there are only few projects specifically focused on gender. There is a need for disaggregated data. There are also some institutional challenges in recruiting women to more senior positions. Gender will remain a focus point of the federation.

**ACTION:** TLMI will feed back on their gender survey once completed.

10. Upcoming events and next steps

Most members thought it was important to have two face-to-face meetings of the MA each year. Interim meetings could be held at other events.

The MA agreed that the Panel should meet face-to-face twice a year and the ITC would meet at least once, and a second would be considered if there was a need.

The next meeting will be held on 18, 19 and 20 October 2017 in Würzburg, Germany, hosted by DAHW.

For the 2018 Meetings, Lepra and ALRA will be asked to consider hosting. This will be confirmed, along with dates.