Expected outcome of session:

Members receive CEO report

Members advise CEO on

a) Priority focal areas for CEO to March 2019

b) ILEP position on WHO guidelines

c) Requests by Alice Cruz
ILEP CEO’s report to Members’ Assembly
October 2018

Vision
A world free from leprosy

Mission
To work together to stop leprosy, to prevent disability and break the stigma resulting from leprosy

Strategic Goals: What the ILEP Federation aims to achieve:
1. We will work together and with other partners to stop the transmission of leprosy.
2. We will work together and with other partners to prevent disabilities from leprosy.
3. We will work together and with other partners to promote inclusion of people affected by leprosy

Enabling Actions: How the ILEP Federation will achieve these Strategic Goals
1. We will improve ILEP collaboration to achieve our Strategic Goals.
2. We will work in partnership with others to achieve our Strategic Goals.
3. We will raise the profile of leprosy and its consequences to achieve our Strategic Goals

Operational Aims: How the ILEP Office will facilitate this strategy:
1. ILEP Office will facilitate effective governance of the ILEP Federation.
2. ILEP Office will coordinate the Federation to monitor achievements and promote learning in the attainment of the ILEP strategy at national and global level.
3. ILEP Office will lead the development of policy, advocacy and communication initiatives in collaboration with the Members.

This report contains three elements.

Section A is an updated report of achievements framed around the Operational Aims in the 2018 workplan.

Section B talks about my expected focal areas for the next six months.

Section C looks at a number of external developments over the past six months that may be significant to ILEP.

A. Achievements against Operational Aims
### Strategic Objectives

<table>
<thead>
<tr>
<th>ILEP Operational Strategy: Workplan 2018</th>
<th>Qtr 3 Report to the MA</th>
<th>Sept</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
<th>Reflections /Comments</th>
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<tr>
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<td>Preparations have gone well in association with DFB for the October Members’ Assembly and accompanying meetings (ITC, Panel, Country Coordination), the cocktail function with Princess Astrid, and following directly on, the GPZL leadership team. Papers were sent to MA on time. The constitution and Bye Laws have been updated to remove inconsistencies.</td>
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<tr>
<td>Report from MA meeting, Preparations for possible Learning Event in Q1 2019</td>
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<tr>
<td>Logistics info and planning for March MA and connected meetings</td>
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<td>Having two Members’ Assemblies a year seems to be valued by Members and is beneficial at a time of change (GPZL). This pattern is planned again for 2019. We have ensured that the key strategic topics take priority in the MA agenda and that adequate time is devoted to them. The CEO Summit in September 2017 seems to have helped in mutual understanding, but less so in terms of ILEP’s future role. There is still a big difference in what Members what and expect from ILEP. It is recommended that another CEO Summit happen in March 2019 by which time GPZL is better developed. We have tried different approaches with a ‘learning event’ or conference (previously co-operation meetings). Tanya questioned whether we have found the right formula for these. I think the effectiveness of Federations is boosted by linkages at many levels, and that includes opportunities for technical people from all Members to get together to discuss key topics. It may have been a mistake not to have such an event in October 2018 and we should consider whether there is benefit in doing so in Q1 2019 as well as Q4 2019.</td>
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| 1.1.2 Board meets regularly with up-to-date reports and documentation from the office |
| Board involved in recruitment of new CEO. Nominations for President and Board positions called for. Schedule of Board terms clarified. Improvements to the content and regularity of the financial reports that go to the Treasurer. |
| Board call prior to extra MA meeting |
| Board meeting 1 Oct to discuss budget. Board dinner 9 Oct Elections for President and Board |
| Board call 6th Dec |
| Board quarterly Skype meetings have been suitable for the amount of follow up required at the governance level. |

| 1.2. ILEP’s Advisory Bodies are providing feedback to the ILEP Federation |
| 1.2.1 ITC has a clear workplan in support of the ILEP strategy and Triple Zero campaign |
| ITC individuals have done a number of pieces of ILEP work - Stats document, leadership on Uniting to Combat (London Declaration) action framework, engagement on WHO TEG, developing the TEG for the stigma guidelines. No clear work plan as yet, but close association with the developing work of GPZL |
| Agenda developed |
| ITC meeting |
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### ILEP Operational Strategy: Workplan 2018

#### Operational Aim 1: (Governance): ILEP office will facilitate effective governance of the ILEP Federation

1.1 ILEP’s governance bodies are effectively overseeing and guiding the Federation

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1.2.3 Panel has a clear workplan in support of the ILEP strategy and Triple Zero campaign

Mathias has included Panel on discussions around engagement with the GPZL and presented statement on behalf of the Panel at the Human Rights Commission. Mathias is developing his own work in his consultant capacity and considering the review of the Chair role to bring back to the October MA. Mathias led engagement by persons affected at NNN (September 2018)

<table>
<thead>
<tr>
<th>Agenda developed</th>
<th>Panel meets</th>
<th>Ongoing work on participation and other topics from Panel and MA meetings</th>
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<tr>
<td></td>
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<td>The Panel has developed to become a key ILEP structure in a short space of time. A lot of this is credited to Mathias’s drive and commitment, but we have to be careful that the Panel is ‘more than Mathias’ - new ways of engaging with the other Panel members may be needed. Meeting twice a year in conjunction with the MA seems good. There is a valuable opportunity for ILEP to develop the Social Inclusion Framework with the Panel. Some progress has been made on this but (like with the Participation Policy) progress is slow and support is needed by the ILEP office (around half a day per week). With Nathalie’s departure from the staff team, this now falls mainly to the CEO.</td>
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1.3. ILEP has produced and is delivering a new Membership Strategy

1.3.1 Membership matters, including new strategy, is followed up

No action to report

This is an area where various pieces of work have been done over the last few years looking at the role of ILEP, who should be members of ILEP, the fee structure etc. This has concluded in maintaining the status quo - which currently seems the best option: the wider membership-base of the GPZL means that ILEP can focus mainly on representing the INGOs

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### Operational Aim 2: (Coordination) ILEP office will lead improved coordination with ILEP Countries and Partners

#### 2.1 ILEP office monitors and reports on progress against the Strategy

2.1.1 ILEP annual report charting progress is produced and disseminated

Conversations (face to face where possible) with each of the ILEP CEOs. London Declaration/ILEP Annual Report Survey went to Country Coordinators. This fed into the London Declaration (Uniting to Combat NTDs) meeting in September in Amsterdam and to updating the ILEP website. Geoff and Monty represented ILEP at the Uniting to Combat NTDs meeting in September. This was quite different from previous meetings: focused not on data but on adequacy of health systems, capacity, funding etc. Geoff has been involved since the meeting in making the Committee-produced documents coherent and then editing them to take account of the feedback from various sources.

- London Declaration/ILEP Annual report survey went to Country Coordinators to feed into the two reports.
- London Declaration (Uniting to Combat NTDs) proxy action framework meeting and report.
- ILEP Strategic Options presented to Members’ Assembly
- Scoring work on the Uniting to Combat Quantitative Scorecard
- Work starts on the ILEP Annual Report 2018
- Further development of strategy following MA discussion on strategic options
- Work continues on the ILEP Annual Report 2018

The main value of having an ILEP strategy and annual report has been:

1. to show the alignment of ILEP Members in terms of strategic intent and achievement
2. to show differences between ILEP’s strategy and the strategies of others such as WHO and the GPZL. These differences are now much reduced, there is growing strategic convergence
3. communication framework to promote the triple zero strategy and the work being done in each of those areas by Members on our website and through the monthly updates.
4. Data collection as an aid to reporting to the London Declaration Scorecard report. This now appears redundant, as the WHO data is being used for this purpose.

The challenge is that ILEP’s strategy has a large number of indicators which we have carefully reported on each year - but with limited “impact” or follow up, because essentially these indicators are about the work of the Member associations. This needs ongoing reflection: are we planning/reporting on ILEP-as-Federation or on ILEP as the sum total of its Members' programs?

Suggestions for going forward are included in the Strategic Options paper.
### 2.2 Improved internal and external communications

#### 2.2.1 Twelve country plans have been produced and reports provided

<table>
<thead>
<tr>
<th>Alex, as Coordination Champion, has actively engaged to progress country coordination, including...</th>
<th>Country Coordination data collection completed and seeking stories on best practice</th>
<th>Follow up on the draft country plans</th>
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</table>
| - working with Monty on updating the country coordination pages on the website  
  - planning for the Senegal and Nepal country coordination meetings for October  
  12 country plans will not be delivered in 2018 (see APR Report for a list of completed and draft country plans) | Preparation for October meeting | |

#### 2.2.2 ILEP is maintain a well organised website and communication tools

| Preparation underway for WLD 2019 with the comms network. The focus is on stigma, prejudice and discrimination. It will include a report similar to the gender one on triple jeopardy. This has been done in association with the Panel and with Wim van Brakel with feedback from Members.  
Website is up to date and ILEP maintains an active social media presence. Substantial time spent in August on ensuring GDPR compliance. There are some technical challenges over the map which we are resolving.  
Comms network is active and meeting regularly. Institutional fundraising group has been convened, meeting quarterly and attracting new members. It is well-attended | WLD work. Preparations for NNN (this was a major focus for Rosa in September)  
At NNN (Addis), in addition to being NNN comms lead, Rosa and Nathalie led workshops on comms: perhaps the best attended workshop at NNN | Under Rosa’s leadership the whole Comms area is functioning extremely well. Rosa has also been involved heavily leading Comms for NNN during Tanya’s chairmanship, and I am proposing for this to continue (though with lower intensity)  
We have recruited an intern for 3 months under an arrangement we have used several times with a US University. She will focus mainly on communications. |
|--------------------------------------------------|--------------------------------------------------|-----------------------------------|
### 2.3 Office systems and process in place to deliver on strategy

**2.3.1 Office is well staffed to deliver on the strategy**

New CEO appointed and taken up the role, all the necessary paper work ongoing and handover with the previous CEO completed. Stable staff team, but reduced by 0.2 when Nathalie (who works mainly to support Mathias) finishes at the end of September.

**Development of 2019 financial plan**

Agreement on 2019 budget at the MA. New fiduciary appointed (HR, accounts, legal)

Over the past 3 years there have been a number of changes in staffing in the ILEP office (two technical advisors, three comms staff, various interns, and consultants to fill gap). With such a small team staffing changes have been more consuming than we all would have liked. There is now a good staffing in place with Rosa and Monty. At present, there is ample work for a full time CEO.

The size and location of the office and maintaining an independent structure (ie separate from any of the Member associations) will continue to be a point for discussion, to balance the cost versus the effectiveness and impact.

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### Operational Aim 3: ILEP Office will lead the development of policy, advocacy and communications initiatives in collaboration with the Members

#### 3.1 ILEP office has led an increased number of policy, advocacy and communication initiatives linked to Zero Transmission with members and partners

**3.1.1 Transmission Key Initiative: Global Partnership for Zero Leprosy is established**

This quarter has seen the GPZL develop and get the planned work under way.

- Recruitment of Christine Fenenga for the Op Excellence Coordinator, accountable to the Task Force for Global Health and funded by ILEP.
- ILEP engaged in the discussion and composition of Working Group 1 (Research).
- MoU signed with GPZL and ILEP funding till Dec 2018 approved. Funding to Dec 2019 needs to be agreed at MA meeting in Oct 2018.

End of Aug - initial meeting on Research Working Group and OP Excellence group.

ILEP fundraising needed for GPZL secretariat 2019

GPZL Leadership team meet directly after ILEP MA.

ILEP confirms funding for GPZL Secretariat for 2019

GPZL Research Agenda proposed.

Working Group 3 (Resource Mobilisation) formed

GPZL Research Agenda agreed, beginning process of building investment case.

Working Group 2 timeline and Toolbox structure agreed

The GPZL has been the most substantial new development in the leprosy world in recent years. Established in March 2018 it has got "up and running" in Q3 2018. The role, activity, business plan and costs of the GPZL Secretariat will be a major focus of the MA meeting in October.

One of the challenges of these developments is keeping ILEP Members well informed on what the GPZL is, what it is doing, and what it achieves. These are key responsibilities for ILEP Secretariat.

#### 3.2 ILEP office has led an increased number of policy, advocacy and communication initiatives linked to Zero Disabilities with members and partners

**3.2.1 Disabilities ILEP Initiative: Determined, planned and proposed**

Nothing to comment

Zero disability’ has not had momentum in terms of ILEP Office engagement, although disability has remained an important aspect of Members’ work. I will start to change this by greater engagement with IDDC, but Members should recognise that Zero Transmission is the primary initial focus of the GPZL and, because of the amount of ILEP Office time engaged with GPZL, disability will still have less priority. Jannine Ebenso (TLMI) takes the primary role here.
### 3.3 ILEP office has led an increased number of policy, advocacy and communication initiatives linked to Zero Discrimination with members and partners

#### 3.3.1 Discrimination ILEP Initiative: Determined, planned and proposed

<table>
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<tr>
<th>Activity</th>
<th>Details</th>
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| Nathalie and Mathias have continued to increase focus and attention on initiatives related to Social inclusion and Zero Discrimination. These include: | - Developing a proposal for an ILEP policy on participation of persons affected  
- Continued discussion and engagement with Alice Cruz to support and promote her mandate  
- Continued effort to try and connect with broader NTD community on this area, including substantial efforts before and during NNN.  
- Engagement in planning for stigma guideline TEG meeting |

| NNN meeting: Mathias led one workshop session 'Nothing about us without us' and heavily involved in promoting participation | Further work on participation policy and social exclusion framework |

**This is an area where there has been continued momentum built in the last three years, with the panel, but also with other opportunities around the UN and the Special Rapporteur role, as well as members (particularly TLMI) engaging at an advocacy level.**

There are the bones and structure of an ILEP social inclusion framework which will be further developed with the hope of offering the ILEP Members something they can adopt as a shared approach to social inclusion. This is an area ILEP Office will continue to take a leadership role in.

ILEP participation policy should be ready for circulation early 2019 with the hope of adoption in March 2019.

#### 3.4 ILEP office has led an increased number of externally-oriented international policy, advocacy and leadership roles which enhance the work of the Federation

#### 3.4.1 ILEP has taken a leadership role with NNN and Uniting to Combat

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| NNN conference plans underway with an expectation of double the turn out of previous years (400+) | * Uniting to Combat going through a number of reviews - both for the Scorecard as well as future of partnership  
* Leprosy lead in NNN will revert from Pete Garratt to ILEP CEO after the Sept NNN meeting |

| NNN Conference  
Uniting to Combat action framework meeting (leprosy section) | Further work on participation policy and social exclusion framework |

**NNN has been a substantial aspect of ILEP work these last two years which has led to the following positive outcomes:**

1. we have raised awareness of leprosy in the broader NTD circles, what we are doing, what our challenges and potential is.
2. we have many ILEP members actively engaged /taking leadership with some of the NNN cross cutting groups - particularly around disability and inclusion where leprosy can and should take a leadership role.
3. we know the NTD community a lot better now, how they function and where we can learn from them.
4. We have "warm" leads for the future of the GPZL with the Uniting to Combat donors and partners.
B. Focal areas October 2018-March 2019
These are included to enable the Members’ Assembly to confirm whether these should be the CEO’s priorities and what other priority focal areas ought to be added. They are not necessarily ranked in order of strategic importance.

1. Carry through the choices made by the Members from the strategic options presented to the October Members’ Assembly.

2. Maintain regular contact with Member CEOs – face to face or Skype

3. Work with Alex Jaucot, and with the Members in general, to develop coordination, cooperation and collaboration between Members

4. Play a full role as ILEP representative to build GPZL:
   • as Leadership Team member
   • as core funder of the Secretariat along with Novartis Foundation
   • with a particular focus on Working Group 2 (ILEP’s direct responsibility) and Working Group 3 (Resourcing and Advocacy)
   • in contact as needed with Novartis Foundation

5. Form connections with head of WHO-NTD, Human Rights Council, and other relevant UN and WHO officers in Geneva (in association with Pradeep Bagival (TLMI) and others)

6. Participate in WHO SEARO Program Managers meeting in Colombo, October 2018 (Courtenay Dusenbury and Christine Fenenga will also be present) and look for opportunities to engage in or ensure that ILEP is represented in any other WHO Leprosy and/or WHO NTD regional meetings

7. Revise the way ILEP reports on KPIs and strategic achievements starting from the end-points of ‘what do we need to know’ and ‘what do we want to say about ourselves as a federation’ (NB: it is assumed that the ILEP Office will no longer collect country data from Members as before)

8. Keep watching brief on the work of the Stigma Guidelines TEG ensuring a clear focus on the final product being fit for purpose

9. Support Mathias Duck and the Panel in completing the ILEP participation policy and further work on the social inclusion framework

10. Look for opportunities to engage in Zero Disability agenda by building linkages through IDDC etc

11. Review the information ILEP holds on discriminatory laws with the aim of (a) clarifying which are active (b) prioritising what should be tackled

12. Plan for successful Members’ Assembly and related meetings in March 2019

13. Plan, if agreed, for cooperation meetings (technical focus) in first and/or fourth quarters 2019

14. Participate in NNN Executive Committee and follow up promising linkages from NNN 2018
C. **External developments**

This section of the report looks at a number of external developments that have an impact on ILEP.

**NNN**

Around 60 people connected with the leprosy world attended the annual conference of NNN (the NGO NTD Network) in Addis Ababa in September. Some observations:

- There were around 400 attendees, almost double the numbers from 2017. It was good to see Africa very strongly represented
- It was again demonstrated that the leprosy world has a great deal to offer to other NTDs, as well as the opportunity to learn from them. Examples: the number of leprosy-related delegates, leading roles in a range of workshops, the lead shown by persons affected by leprosy, leprosy involvement in the NNN task-groups such as DMDI, etc
- It was good to see the quality of leprosy-related personnel and presentations being exposed not only to the other NTDs but also to potential funder/investors like Gates Foundation and End Fund
- Nine persons affected by NTDs were present (up from one at last year’s conference) and eight of them had leprosy connections. Mathias, Rachna and Amar from the ILEP Panel all had a greater impact than might have been expected from their small numbers. The Executive Committee is putting out a challenge to other NNN members to try to ensure that at least two affected persons from each disease group are present at, and well-prepared for, the 2019 meeting. The afternoon session with the affected persons group, preparing them for the coming meeting, was important
- Tanya, Rosa and Nathalie – all of them heavily involved in conference leadership, communications and logistics – did an excellent job. We can be very proud of the ILEP team
- The disease-specific sessions included two of particular relevance to leprosy:
  - a half-day ILEP workshop, facilitated by Pete Garratt (TLMI) and mainly featuring presentations by Dr Erwin Cooreman (WHO) and David Addiss (Task Force for Global Health) followed, in each case, by a very active Q&A session
  - a half-day DMDI (Disease Management, Disability and Inclusion) workshop in which there are several task groups focusing on different aspects of the disease continuum. This was co-led by Martin Kollmann and Wim van Brakel.
- Building connections between ILEP, its members and persons from the other NTD disease groups is vital. Because leprosy has a low priority for Ministries of Health in most endemic countries, ILEP members can make a difference through collaboration with other NTDs which, in combination, may lift leprosy up the priority list
- The next NNN conference will be in Liverpool, England during the week beginning 16 September. This is the week after the ILC in Manila.

While Tanya has been NNN chair, Pete Garratt (TLMI) has taken the ILEP lead on NNN including serving on the Executive Committee. That role has now passed back to the ILEP CEO.

The final communiqué from the Conference is attached as **Appendix 1**.

**WHO Guidelines**

One of the most striking features, coming back into the leprosy world, has been the very active engagement by WHO Global Leprosy Program, especially Dr Cooreman and Dr Pemmaraju. Erwin would like to have retained Laura Gillini in the GLP but was not able to do that within the available Nippon Foundation funding.
Dr Cooreman presented the new WHO Guidelines to the ILEP group meeting at the NNN conference in Addis: this was a group of around 50 people mostly associated with ILEP members. Some observations from the presentation and discussion:

- These are Guidelines. In WHO terminology, this means they have gone through a rigorous process to ensure they are evidence based. Where the evidence was not strong, some of the recommendations are marked as conditional – but this still means that they are based on the best available evidence and are stronger than any alternative.
- In general, the quality of leprosy research is weak. This is why the evidence base was not very strong for the Guidelines. We need to ensure that the future research is of better quality.
- Ministries of Health are not obliged to follow the Guidelines. Leprosy Program Managers may not be inclined to adopt the new recommendations. It is likely to fall to the responsibility of the ILEP coordinator, and other ILEP members in the country, to encourage and support adoption. It seems to me that this is one of the key indicators of ILEP cooperation. It will be the same again when it comes time to implement the practices in the GPZL Operational Excellence toolkit at country level.

ILEP members are not likely to encourage and support adoption of the WHO Guidelines unless the ILEP members themselves accept the Guidelines. What is ILEP’s position on this?

Special Rapporteur for the elimination of discrimination against persons affected by leprosy and family members

Alice Cruz has written a brief address to the Members’ Assembly which is Appendix 2. She asks for ILEP’s support in three areas:

- The consultation she is planning with states and civil society, and with persons affected, for her next report
- Obtaining official invitations to visit endemic countries to produce country reports. She has sent requests to India, Indonesia, Brazil and Ethiopia. I understand she has recently received an invitation to Ethiopia.
- Her plans for a meeting with persons affected and key stakeholders at the Human Rights Council session in 2019.

I appreciate to have the Members’ Assembly’s view on these requests.

Uniting to Combat NTDs

In previous years this report was a simple ‘traffic light’ scorecard, which was not very usable. This year, it is divided into two sections. The first, called ‘action framework,’ describes the status of world leprosy from three main perspectives:

- Enabling environment, which includes financing, health information systems, access to drugs and technologies, health workforce and scientific understanding
- Strategy, which includes leadership and governance, guidelines, collaboration and innovation, and integration into national health systems
- Public health intervention, which includes service delivery and sustaining impact

The action framework report for leprosy was drafted by key NGO stakeholders including ILEP in September and a final version has been submitted to Uniting to Combat, which is housed in the Task Force for Global Health. It is a detailed spreadsheet, so I have not attached it but any Members who would like to see it are welcome. What was to me very impressive was how this framework now
converges with many of the other workstreams in leprosy: the same questions and the same issues are highlighted in many different forums.

The second section, the data outputs, will be done later using primarily WHO data.

**IDEA strategy**
IDEA has undertaken a strategic planning process facilitated by Marie Staunton. They have sent a copy of the resulting strategy 2018-2021, which is attached as Appendix 3.

**Mental wellbeing and leprosy**
Members will be aware that this is an area of increasing focus, associated with (but not the same as) stigma and discrimination. A consortium of organisations working in this area formed a Task Group on Mental Wellbeing and Stigma last year under the umbrella of the NNN. In 2018, a group led by CBM, Lepra and Brighton and Sussex Medical School, started working with the WHO to develop a manual for implementers and governments to carry out effective mental health work as an integral part of their NTD programmes including leprosy. This is expected to be ready by the end of 2019, and to guide practical support for people doubly disabled by both NTDs and negative mental health impacts.
**APPENDIX 1**

**NNN 2018 Conference Communique**

*Reaching the last billion - setting BEST in motion*

During its 9th annual meeting, the NNN met in Addis Ababa, Ethiopia, 24th-26th September, hosted by the Ethiopia Federal Ministry of Health.

The NTD community recognises the important role it has to play in combating inequity and contributing to improved health status and inclusion of people affected by NTDs. We are committed to breaking down the barriers that hamper access to health and support services for people affected by NTDs.

NNN members are unified in the goal of reaching and empowering the most marginalised populations. We know that targeted approaches and prioritising equity and inclusion are critical to strengthening our work with women, people with disabilities, those affected by poor mental health and stigma, people in conflict-affected and fragile areas, migratory populations and out of school children. NNN members recommitted to action to reach these marginalised groups through enhancing the efforts of our existing disease-specific and cross-cutting groups and establishing new working groups on Sustainability, Conflict and Vector Control, Skin NTDs and One Health.

We recognise the agency and leadership of people affected by NTDs and the importance of ensuring that their voices are heard in NNN meetings and other relevant forums, and that their perspectives inform the work of the network.

We recognise the importance of cross-sectoral action on NTDs, including collaboration on WASH, education, veterinary public health and vector control, and call on all NTD funders and implementers to support such collaboration through suitable governance and financial mechanism. We will continue to advance progress on NTDs through development and sharing of best practices on joint monitoring, behaviour change and cross-sectoral partnership development.

In an effort to support NTD action for achievement of the Sustainable Development Goals, we will promote and implement practices that strengthen national health systems and secure sustainability of the impact of NTD interventions.

In the year ahead, the NNN community will continue its commitment to achieving progress on all components of the BEST (Behaviour, Environment, Social inclusion and equity, Treatment and Care) framework.
Dear ILEP

Member’s Assembly, Executive Board, Panel of Women and Men Affected by Leprosy, Technical Commission,

It is my great honor to address you all. I had the privilege of joining you during your last meeting and I take now the opportunity of your present meeting to update you on the work of the mandate.

As you know, I have presented my first report to the Human Rights Council last June. I am now developing the outline for my next thematic report. The report will address structural and interpersonal stigma, its causes and consequences, in women and children affected by leprosy, including family members. I will make two consultations for the report. One designed for States and civil society, and another one for persons affected, their family members and carers. I kindly ask for your extremely important cooperation on both consultations. I will send you both questionnaires in the upcoming months and hope you can assist me in collecting this crucial and much needed data.

One of the biggest challenges of my mandate regards official country visits. As you may know, official country visits are of the outmost importance, since they allow for producing a country report, which cannot be ignored by the respective State. However, official country visits only take place at invitation from the government. So far, I have sent requests to India, Indonesia, Brazil, Ethiopia and Nepal. I have not received any invitation
so far. I kindly ask for your support on this sensitive issue, also in sharing your views on other countries you may regard as important for me to visit.

Finally, I would like to share with you that I am planning for a meeting with persons affected and key stakeholders to be held next year in Geneva during the period of the Human Rights Council's session. I am still developing the outline of the meeting, but the goal is set for raising awareness on leprosy among States, the Human Rights system and community, and civil society organizations. For that end, it would be very important to make the voices of persons affected and stakeholders working on the ground heard. Again, I kindly ask for your cooperation in this issue. Once I have more concrete details, I will be asking for your views, advice, participation and support.

Thank you for your support to my mandate. Your inputs, suggestions and recommendations are always welcomed and much appreciated.

Warm regards and wishes of a great meeting,

[Signature]

Alice Cruz

Special Rapporteur for the Elimination of Discrimination Against Persons Affected by Leprosy and Family Members
Inclusion is Our Language

Strategic Plan for International Coordination

2018-2021

International Association for Integration, Dignity and Economic Advancement, IDEA
EXECUTIVE SUMMARY

IDEA is the first international advocacy organization and network of support led primarily by individuals who have experienced Hansen’s disease/leprosy. Since its founding in 1994, IDEA has promoted the inclusion of people in all areas related to Hansen’s disease/leprosy, from the local to the global level. For the past 15 years, the coordination of IDEA’s international activities has taken place through its headquarters in the United States in the state of New York. As of June 2018 these headquarters will transition to the state of Massachusetts.

Over the last several years, income to coordinate and implement these activities has gradually shrunk as a result of several factors, thereby stagnating IDEA’s growth and threatening the existence of the organization today. To sustain its operations, IDEA initiated a strategic planning process to articulate its programming, and develop a plan to ensure that the necessary governance, leadership, and communications are in place for its successful future. Most importantly, new funding streams and partners must be identified to provide for the financial stability of IDEA’s evolution. To address this, IDEA will implement a three year actionable plan for its international headquarters.

The strategic plan defines IDEA’s areas of expertise as follows:

1. Advocating for people’s inclusion and human rights
2. Fostering the empowerment of people in their daily lives—socially, physically and psychologically-- through programming such as women’s programs and psychosocial services
3. Furthering opportunities for leadership and developing new leaders
4. Promoting recognition and respect of people’s experiences, and through this understanding affect positive change including World Heritage for selected heritage sites

As part of the plan, IDEA’s infrastructure will be strengthened as follows to support these areas of expertise.

1. A governance plan to address Board succession, accountability and transparency
2. Expanded financial systems to ensure accountability and transparency
3. A funding plan to increase and diversify IDEA’s income to cover expenses and ensure sustainability
4. A communications plan to increase awareness of IDEA’s activities among its branches, members, funders, the general public and Hansen’s disease/leprosy, human rights and NTD related organizations.

These steps will ensure that in three years IDEA will be a financially sustainable organization; with an accountable and transparent Board and financial reporting; and a balance of seasoned and emerging leaders, representative of people from different countries and experiences. IDEA International will be viewed as a credible and integral organization within the field of leprosy, with sustainability of its international programming in the areas of advocacy, empowerment, leadership, and heritage and education, and support of the development of local programming in these areas and other locally identified needs. This approach will ensure the successful future of IDEA in fulfilling its vision of a

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1 The word “people” throughout this document refers to individuals who have experienced Hansen’s disease/leprosy.
world where the inherent dignity of all human beings is respected.

To reflect IDEA’s approach, the tagline “Inclusion is Our Language” has been created. In this context language is how we communicate with each other, both in our words and actions.

**EVOLUTION**

Over the nearly 25 years of its existence, IDEA’s focus has evolved, reflected in its areas of expertise as follows: advocacy leading to people’s active participation in key meetings of ILA Congresses, ILEP, and WHO, and standards set on respect of people’s human rights; fostering empowerment of people through psychosocial and women’s programs developing local and international leaders; building a network of mutual support; producing exhibitions and publications on the heritage of Hansen’s disease/leprosy, to promote understanding of and lessons learned from people’s experiences.

IDEA currently has 24 branches, covering five continents, with international headquarters based in the USA. IDEA’s Board of 14 Directors employs one part-time International Coordinator who oversees programs on research on implementation of human rights standards, international advocacy, reunification of people with their families, capacity building and support of the global network. IDEA has Special Consultative Status with the Economic and Social Council of the United Nations.

**RENEWAL**

In 2017 IDEA’s Board Members decided to refresh its leadership and develop a strategy to respond to a changing environment and diminishing funds. It embarked on a nine-month strategy process which included a review of the external environment; critical self-reflection based on input from members and partners on strengths, weaknesses, opportunities and threats and; interviews with key external partners on IDEA’s role and effectiveness, culminating in a strategy workshop in June 2018 which produced a new strategy for 2018 to 2021 for its international headquarters.

**IMPLEMENTATION**

Goals and indicators for activities have been agreed upon and the strategy will be implemented through an action plan. The Board has initiated this strategy through building its capacity in governance by electing new Board Members; appointing a new International Coordinator; and moving the international headquarters from New York to Massachusetts.

**THE WORLD WE WANT TO SEE**

**VISION:** A world where the inherent dignity of all human beings is respected.

**MISSION:** We create a network across the world of persons who have experienced Hansen’s disease/leprosy and their family members, to empower each other, to ensure human rights and to promote inclusion.

**VALUES:** Inclusion, respect, dignity, dialogue, and justice.
HOW WE WILL MAKE CHANGE HAPPEN?

The following four goals have been identified for IDEA’s international headquarters 2018-2021 strategy.

**ADVOCACY**

**Goal** To advocate for inclusion and the human rights of people

**Objectives**

- Agree on IDEA’s position on the work of the Global Partnership for Zero Leprosy Transmission by December 2018
- Influence the research undertaken by LRI on stigma by December 2019
- Influence the WHO Global Leprosy Strategy 2020 to 2025 by December 2019

**Activities**

*Global Partnership position*: Solicit input from members and Board, September 2018

Skype call with 3-4 Board members to develop IDEA position, October 2018

IDEA Representative to Partnership report to IDEA Board, November 2018

*LRI Research*: Complete LRI research on human rights, analyze results, and develop activities based on outcomes by December 2018

Conduct session on LRI research at ILC, September 2019

Propose research topics to LRI by December 2019

*WHO Global Leprosy Strategy*: Develop partnership with WHO by December 2019

Develop Members only section on website to promote advocacy by December 2020
EMPOWERMENT

Goal  To foster empowerment of people in their daily lives-socially, physically, and psychologically

Objectives

➢ Three IDEA branches develop psychosocial services skills (e.g. counselling and support groups) by December 2020

➢ Investigate feasibility of linking older people in communities in Japan with young members from other countries by December 2020

Activities  Psychosocial skills: Organize empowerment workshop in India for women to exchange experiences and increase well-being by December 2019

Organize an exchange on development of psychosocial services between Brazil and India by December 2019

Develop and disseminate a good practice booklet on the web and in print on how to develop local psychosocial services by December 2020

Japan Exchange: Research logistics and budget for international exchange for young people with experience of Hansen’s disease/leprosy to communities in Japan by December 2020

Indicators  Evaluations of effectiveness of workshop and psychosocial exchange Booklet downloads

Budget  Empowerment workshop: $6,000  Psychosocial exchange: $6000  Booklet: $8000

Responsibility  Psychosocial skills-International Coordinator, representative from Brazil, representative from India; Japan exchange-President for Heritage and Education

LEADERSHIP

Goal  To develop new local and global leaders and further opportunities for leadership

Objectives

➢ Capacity building workshop for 10 IDEA members, representatives from four peoples organizations and/or potential leaders at ILC, September 2019

➢ Develop IDEA members’ role as Experts by Experience through formalized program by December 2019

➢ Develop new leaders in three countries and renew leadership in three IDEA branches by December 2020 by Picking the right people, Priming them with IDEA’s programs and
objectives, Pulling them up to take responsibilities and develop skills, Pushing them up to
decision-making and executing positions

**Activities**  
*Capacity building workshop*: Identify qualities, capabilities and capacity building needs of IDEA leaders by December 2018

Identify IDEA members and representatives of peoples organizations to participate in workshop by February 2019

Design workshop by May 2019

*Experts by Experience*: Identify experts by February 2019

Develop Experts by Experience session for ILC including Experts from another field by May 2019

*Expert Exchanges*: Conduct three expert exchanges to Sri Lanka, Bangladesh and Madagascar to identify local leaders, and share values and expertise between countries by December 2020

Investigate possibility of Speakers Bureau by December 2020

**Indicators**

Capacity building-evaluation of ILC workshop by participants; numbers participating

Experts by Experience-number identified; number requested to contribute to other organizations' work

Local leaders identified for Sri Lanka, Bangladesh and Madagascar

Succession of leaders in three countries; successors develop and start implementation plan for their country

**Budget**  
*ILC leadership workshop*: $50,000  
*Expert exchanges (3)*: $12,000

**Responsibility** International Coordinator, President for Heritage and Education

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**HERITAGE AND EDUCATION**

**Goal**  
To promote recognition and respect of individuals’ unique experiences, and through this understanding affect positive change

**Objective**

➢ To gain transnational World Heritage status for five leprosy heritage sites by 2023

**Activities**

Build awareness in heritage community and other sectors, participating in one international conference per year 2018-ongoing

Formalize a resource group of people who have lived at leprosy sites and an expert advisory group by December 2018

Obtain letters of intent from five interested sites by February 2019

Hold heritage meeting at ILC, September 2019

Conduct two sites visits, Hawai‘i and Australia by November 2019

Develop resource packet for heritage sites by December 2019

Investigate separating IDEA Center for the Voices of Humanity from IDEA by December 2019

Upload oral history to heritage website by December 2019

Collect documentation and verify sites by December 2020
Facilitate four-day training for resource and advisory group on how to submit an application by **December 2020**

**Indicators**
- Annual participation in one international conference
- Resource and expert advisory groups established and have met annually via video-conferencing or in-person
- Letters of intent obtained
- ILC heritage meeting held
- Two site visits conducted
- Resource packet published
- Oral history uploaded to web site
- Sites Designated
- Training conducted

**Budget**
$37,500

**Responsibility** President for Heritage and Education; International Coordinator; Heritage Advisor

**HOW WILL WE CHANGE OURSELVES?**

The following four supports will be addressed in IDEA’s international headquarters 2018-2021 strategy.

**GOVERNANCE AND FINANCE**

**Goal**
To ensure accountability and transparency

**Objectives**
- To ensure clarity about IDEA’s governance and finance to IDEA Board, branches, current and potential funders, partners and the public
- To establish and maintain financial systems that conform to generally accepted accounting principles (GAAP), meet the Financial Accounting Standards Board (FASB) standards, generate information necessary to file the annual federal government Form 990, provide accurate and timely information to produce reports for Board and funders, and maintain financial accountability—June 2019

**Activities**

*Governance*
- Appoint new Board members and officers—completed June 2018
- Create and appoint President for Heritage and Education—completed June 2018
- Appoint Board Member as liaison to International Coordinator for strategic plan—completed June 2018
- Communicate Board Member update and strategy to partners—August 2018
- Conduct a minimum of two Board meetings per year—next scheduled Board meeting November 2018 via videoconferencing; in-person meeting at 2019 ILC September 2019
- Appoint independent Board advisor—December 2018
- Conduct governance self-assessment—December 2020

*Finance*
Implement the following systems throughout 2018.

Work with SCORE (Service Corps of Retired Executives—a volunteer network of experienced business professionals) to develop transparent systems.

Create four financial reports—September 2018
*Statement of Financial Position
*Statement of Activities
*Statement of Cash Flows
*Statement of Functional Expenses

Prepare 2019 annual budget—September 2018

Monitor budget monthly—beginning February 1, 2019

**Indicators**

**Governance**
Partners updated regarding new Board Members and strategy
Two Board meetings per year conducted
Independent Board advisor appointed
Governance self-assessment conducted

**Finance**
Financial reporting system with four reports implemented
Annual budget created

**Budget**

**Responsibility:** International Coordinator

The following chart was developed to reflect IDEA international’s structure.

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**FUNDING**

**Goal**
To ensure sustainability

**Objectives**

- To diversify funding by identifying a minimum of one new partner.

- To ensure that 20% of funds raised is allocated towards expenses for supports and overhead each year
To agree on an annual Development Plan by December 2018

Activities

Develop and/or renew financial support for programs from ILEP and non ILEP leprosy related partners (TNF, PLF, Cardinal Leger, Novartis)—ongoing

Influence Global Partnership for Zero Leprosy Transmission to include funding for advocacy, empowerment and leadership on their platform—November 2018

Develop on-line and social media—December 2019

Investigate crowd funding

Offer opportunity to donate through web site including One Hour for Justice

Research GlobalGiving and other internet appeals and Amazon smile

Research direct mail with bank insert—December 2019

Research and establish support from local and international corporations including pharmaceutical industry, particularly those with operations in countries where IDEA is active—December 2019

Continue to research and identify potential international, national and state private and government foundations to obtain funding from one new foundation per year—December 2019

Indicators: Income raised covers program, system and overhead expenses

Budget

Responsibility: International Coordinator

HUMAN RESOURCES

Goal

To have the right people with the right skills in the right places

Objective

To evaluate current administrative structure to ensure adequate staffing for successful implementation of strategic plan by October 2018

Activities

Review staff roles and responsibilities—October 2018

Evaluate salary and benefits—October 2018

Review FTEs and allocation of time for areas of expertise for each staff person—October 2018

Indicators: Evaluation conducted

Budget

Responsibility: International Coordinator

COMMUNICATIONS

Goal

To increase awareness and understanding of IDEA International
Objectives

- To finalize communications plan to systematically inform and update IDEA branches, supporters, donors, and individuals and organizations within the fields of leprosy, human rights, NTDs and other related areas by September 2018
- To enhance print and web, and develop social media presence throughout 2018 and 2019

Activities

Produce publications including the following.

*Annual report 2017—July 2018
*Semi-annual communication, “The Network”—November 2019
*Press releases and articles with goal of two minimum per year for external web sites and leprosy-related publications including ILEP News and LML—December 2018
*Annually review and update if necessary IDEA collaterals (language and image guidelines, PowerPoint, general brochure, one-page IDEA description, human rights brochure, and heritage brochure)—December 2018
*Translate relevant collaterals into frequently used languages—December 2019

Update, expand and maintain on-line presence

*Create and maintain new user-friendly web site that includes members-only communication) and includes methods to drive traffic to website—August 2018
*Ensure related organizations have links to IDEA web site—September 2018
*Encourage organizations and individuals to add link or widget on IDEA their web site—September 2018
*Use Facebook, Twitter, YouTube and other social media as determined by effectiveness and resources; increase on-line recognition of IDEA through Google Ad Grants and Facebook’s Causes—December 2018-ongoing

Create 25 year recognition booklet, highlighting landmark achievements—September 2019
Develop methods to improve communication and foster exchange of ideas and collaboration among IDEA leaders (individuals, IDEA Representatives, Board Members) including web-based communication—June 2019

Indicators

Completed annual report
Restart of “The Network”
Two or more press releases and/or articles published annually
Completed web site
Number of times web site accessed by members
Number of web site visits
Completion of 25-year booklet

Budget

Web site: $6,000; Booklet: $8,000

Responsibility: International Coordinator; 25 year booklet: President of Heritage and Education
WITH THANKS

IDEA thanks its donors over the past 25 years, all members and partners who participated in interviews for the strategy, facilitator for the strategy, past and present Board Members, staff, and those who have gone before us and continue to inspire.

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IDEA is a United States federally tax exempt non-profit organization.

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