ILEP Members’ Assembly
Brussels, 10th October 2018

Annex: 5a – Strategic Outline for ILEP CEOs, 10.10.2018

Expected outcome of session:
Update the Members on GPZL’s Programme and Business plan
Global Partnership for Zero Leprosy

Seven-Month Update for 2018 / Strategic Outline for 2019-2020

Presented by Courtenay Dusenbury

October 10, 2018
Background on the Global Partnership for Zero Leprosy

The Global Partnership for Zero Leprosy was announced on January 28, 2018 and formally chartered in March 2018 as an association of organizations and individuals committed to ending leprosy (Hansen’s disease). The purpose of the partnership is to facilitate alignment of the leprosy community to accelerate effective collaborative action toward the goal of zero leprosy. It is currently funded by ILEP members and the Novartis Foundation.

The GPZL’s functions and scope were developed following a 2017 survey of 60+ organizations and persons engaged in leprosy and were discussed and approved by its Leadership Team during its inaugural meeting in Colchester, UK in March 2018. The reasons cited for forming the partnership include:

❖ Multi-drug therapy has reduced the global burden of leprosy by 90%, but the number of new cases has remained stagnant for over 10 years
❖ Millions of people continue to live with disabilities and stigma
❖ The current methods and scientific and operational tools are not sufficient and there is not a shared understanding of best practices
❖ Existing funding and methods are fragmented and the total resources needed to address movement forward toward Zero Leprosy in countries and globally is not known
❖ Leprosy is seriously underfunded compared to other Neglected Tropical Diseases (NTDs)
❖ Other NTD partnerships have increased funding by working together across a common platform including those for Lymphatic Filariasis and Trachoma
❖ A bold new vision of moving forward toward a shared goal for leprosy is needed to energize the community and potential new donors

Supporting country-led efforts to move forward along a continuum toward Zero Leprosy is the GPZL’s long-term goal. There is an appreciation amongst the partners that, as is the case for other NTD communities, expectations should be realistic and have a very long-term view. The uniqueness of leprosy and the immensity of the challenge before us is recognized by the GPZL Leadership, which believes that – while daunting – the situation should not be so overwhelming that we don’t try a new, shared approach. Almost every other NTD- and disease-specific group has worked hard over time to unify around shared goals and a joint framework for action. The leprosy community is comprised of committed and creative people working together in good faith. Together, we can benefit from the experiences of others, and learn from their best practices.

Significant time has been dedicated to the Partnership by its Leadership Team, working group chairs and experts, scientists, national program directors and staff, persons affected and program and country-level staff from all over the world. Although too many to mention here, the GPZL gratefully acknowledges all those who are serving on working groups, advising the Secretariat and joining together to support the GPZL vision. Our thanks to ILEP and its members who have contributed financial support and their time and talents to this groundbreaking effort.
**Guiding Principles**

The GPZL Charter, approved by the Leadership Team in March of 2018, states that the following principles will guide the partnership:

- All decisions, priority choices, funding allocation and actions will support the vision of zero leprosy.

- Zero leprosy will not be realized without reducing *M. leprae* transmission. Therefore, a primary focus of the partnership will be to develop the scientific and technical basis needed to accelerate detection and prevention of leprosy to interrupt its transmission, and to scale up innovations at the country program level.

- The partnership will be guided by evidence and reinforced by sharing experience and effective practices.

- Zero leprosy includes addressing issues of stigma and discrimination of persons affected by leprosy, their families, and their communities.

- The partnership will coordinate action among leprosy stakeholders and seek to minimize duplication of efforts among stakeholders.

- The partnership recognizes and supports ownership of national leprosy programs by national governments and will include representation from national programs in its leadership and decision-making.

- The partnership endorses full participation of persons affected by leprosy, including representation on the leadership team and involvement in workgroups and committees.

**Documents that frame the GPZL’s Work**

1. The GPZL Action Framework on page 4 (in the process of being finalized by the Leadership Team) shows the GPZL’s goal and long-term vision.

2. The GPZL 2018 Project Plan. This project plan outlines in detail specific activities and milestones for 2018. It is presented as an attachment and summarized beginning on page 5, including progress to date and potential activities for 2019-2020 that will be discussed by the Leadership Team during its October 11-12 meeting. The 2019 Project Plan will be developed in November 2018.

3. A strategic outline for 2019-2020 and beyond is presented on page 8. The specific milestones for 2019-2020 will be developed with the Leadership Team following the October 11-12 Brussels meeting.
Actio Framework for Zero Leprosy

**2018**
- **RESEARCH AGENDA WORKING GROUP**
  - Aligned Research Agenda for Zero Leprosy
    - Diagnostic tests
    - Post-exposure prophylaxis (PEP)
    - Vaccines
    - Operational research
    - Stigma and disability as barriers to zero leprosy
    - Epidemiologic modeling, investment case and other cross-cutting issues

- **OPERATIONAL EXCELLENCE WORKING GROUP**
  - Toolkit for National Capacity Building for Zero Leprosy
    - Assessment and mapping tools to identify opportunities and gaps
    - Template for visioning and development of 5-year national plans moving towards the goal of Zero Leprosy
    - A menu of best practices, including operational and scientific, for consideration in national plans
    - Country case studies and success stories
    - Developed in partnership with WHO

- **ADVOCACY & PARTNERSHIP WORKING GROUP**
  - Global and national advocacy, partnership and resource mobilization to develop support and funding for: (1) The use of the Toolkit’s menu of options in countries, and the necessary capacity increases to support this, (2) Research priorities and their translation into practice as components of the Toolkit.

**2019**
- **Reconvene facilitators to identify 3-4 priority areas to jointly apply for funding**
  - Proposals submitted and funded
  - Current and new leprosy funds support aligned agenda

**2020 onward**
- **New scientific tools and approaches are tested and inform the Toolkit for National Capacity Building, Country experiences inform the research agenda.**

**2025 & beyond**
- **Countries have measurably improved national capacity in disease surveillance, early diagnosis and treatment (including disease management). They are implementing new scientific tools and approaches. There is a measurable decrease in disability and discrimination, including laws that foster stigma.**

**Ultimate Goal**
- **IN EVERY COUNTRY:** No disease
  - No disability
  - No discrimination
  - No stigma

**Global Partnership for Zero Leprosy**
www.zeroleprosy.org
Project Plan 2018: March 1 – October

During its March 21-22 meeting in Colchester, UK, the GPZL Leadership Team approved a Project Plan for 2018 that includes three major objectives:

❖ Objective 1. Accelerate the research and use of diagnostic and therapeutic tools, interventions and strategies to lead to zero leprosy
❖ Objective 2: Foster a strong, interactive Partnership supported by a credible and transparent governance structure and robust communications
❖ Objective 3: Undertake advocacy and fundraising to ensure support for the Research Agenda and Operational Excellence Roadmap, and sufficient resources for the Partnership and Secretariat to ensure their successful implementation

1: Objective 1: **Accelerate the research and use of diagnostic and therapeutic tools, interventions and strategies to lead to zero leprosy**

Aligned Research Agenda

March-October Update

- The development of an aligned, disease-specific research agenda is a proven way (e.g. Lymphatic Filariasis and others) to bring new donor resources to priority research areas.
- A process to develop a Research Agenda Working Group that could foster discussion, debate and consensus was implemented including terms of reference, operating framework and work plan for the Working Group.
- The original terms of reference developed in 2017 by the GPZL Steering Committee were modified and an open process was used to nominate facilitators and advisors.
- Working group facilitators and advisors convened in Basel August 23-24 and developed methods and a process to ensure comprehensive participation and engagement. Eight sub-groups were created. There was an open call to join the sub-groups. Over 165 researchers and persons affected are now engaged in the effort (a complete list can be found at [http://zeroleprosy.org](http://zeroleprosy.org)).
- The sub-groups met by teleconference and plan to have several more meetings; each group is actively developing their sections of the research agenda. The first draft will be completed at the end of October, with the final draft completed December 15.
- Initial conversations with potential donors have been favorable. It has been stated that the leprosy community’s alignment will be beneficial to seeking additional funding.

Activities proposed 2019-2020:

- The Leprosy Research Agenda will be a key component of the GPZL’s advocacy and resource-mobilization strategy. Under the strategy, donors will be sought to fund its major priorities, and alignment and partnership with existing donors will be facilitated. Initial conversations have taken place with some potential donors, including the Bill and Melinda Gates Foundation and USAID.
- The Aligned Research Agenda will be published in a peer-reviewed journal.
- Materials will be developed to support resource-mobilization and advocacy (along with the business case outlined under Objective 3).
- A smaller group meeting will be convened in early January to develop a process and small groups for proposal development.
- The future role of the Research Agenda Working Group, and the need to align with other groups, will be discussed by the Leadership Team during its October 11-12 meeting.
**Operational Excellence Roadmap/Toolkit**

**March-October Update**

The Roadmap/Toolkit is a way to bring a new long-term vision for the “end game” to country planning. Working within the framework of country assessment and capacity-building is a proven method for attracting the support of new donors (Guinea Worm, Trachoma, Children Without Worms, others).

- A long-term vision for the scope of the Roadmap/Toolkit, and how it will be used to build country capacity, was developed as part of the Action Framework.
- The Terms of reference for the Work Group were finalized and a coordinator hired by ILEP through an open process in August.
- An internal coordinating committee met August 26 and developed a work plan outline and timeline for the committee’s work.
- Committee leaders will be comprised of leprosy program country directors supported by people with specific expertise in the field of leprosy program implementation and organizational development. They will be the facilitators for the Operational Excellence sub-groups.
- An open call for work group participants will be announced in October.

**Activities proposed 2019-2020**

- Dr. Christine Fenenga, the Working Group Coordinator, will convene a meeting in early December to bring together key stakeholders, including national leprosy program directors and WHO. All work will be done within the context of the WHO guidelines and in partnership with its Global Leprosy Programme.
- The Toolkit’s Roadmap (an assessment and visioning tool) will allow for the assessment of country capacity and help envision a future of Zero Leprosy. Strategies that move countries along a continuum toward Zero Leprosy allow national programs to develop long-term goals and fill gaps. In some countries, an “end game” can be near. In others, comprehensive and long-term work will continue.
- The gaps identified in Zero Leprosy plans can be filled with a menu of options and strategies from the Toolkit, along with technical assistance.
- These country-specific “packages” – a visioning plan, and the tools and technical assistance to fill gaps – become the basis for resource-mobilization efforts, both within and outside of countries.
- An online platform will be created to disseminate the menu of tools, methods and best practices. These tools, and technical assistance from the Partnership’s partners, will frame its work during the period mid-2019 onward.
- In 2019, the GPZL will test the toolkit in three countries through a peer/peer assessment and visioning visit and recommendations on best practices/tools.
- Experiences with the Roadmap/Toolkit will be presented and discussed in workshop at the 2019 World Leprosy Congress in Manilla.
- The Road Map and Toolkit will be living products, regularly updated. Over time, the results of funded research and ways to operationalize scientific advances will be added. The Working Group will continue to engage as community of practice with regular exchange through communications platform, teleconference and meetings at other venues (as feasible).
2: Foster a strong, interactive Partnership supported by a credible and transparent governance structure and robust communications

March-October update

- An organizational Charter was developed, revised and approved.
- Structures for systematic communication with the Leadership Team are in place including weekly written updates, monthly calls and bi-annual meetings.
- A strategy for membership is underway and resulting in a strong and engaged network that actively supports the Partnership’s work.
- A comprehensive communications strategy to support network and fundraising goals was implemented including a website, logo, brochure, publications and social media.

Activities proposed 2019-2020

- Continuing to ensure good governance, trust and strong working relationships toward a common goal is a priority.
- A detailed communications strategy that supports network and funding strategies will continue, with a larger focus on resource-mobilization and partnership and in-country advocacy, in 2019-2020.
- The GPZL Secretariat team will transition its program manager to a development assistant, who will provide additional support to the Secretariat Director and Communications Director in identifying and reaching potential partners and key audiences.

3: Undertake advocacy and fundraising to ensure support for the Research Agenda and Operational Excellence Roadmap, and sufficient resources for the Partnership and Secretariat to ensure their successful implementation

March-October update

- During the Colchester meeting, the Leadership Team postponed the establishment of a Working Group on Resource Mobilization to focus on the first two working groups. This working group will be developed and appointed in late October 2018.
- Strategic planning/visioning during the Colchester Leadership Team meeting led to shared goals/objectives for the GPZL and a long-term logic model. Based on these, the Action Framework for Zero Leprosy was developed to align partners in a long-term vision for Zero Leprosy.
- The Action Framework outlines the GPZL’s approach, which includes the development of two products: a Research Agenda and a Zero Leprosy Toolkit for building country capacity, and how these will become the basis for resource mobilization activities.
- A resource mobilization strategy outline was developed and discussed by the Leadership Team and will be finalized during the Brussels meeting.

Activities proposed 2019-2020

- Work with ILEP members to develop a business case for leprosy investment.
- Implement the resource mobilization/partnership strategy to bring additional funding for research priorities and the Roadmap/Toolkit implementation in countries from national and international stakeholders and donors.
<table>
<thead>
<tr>
<th>Year</th>
<th>Phase Description</th>
<th>2018 Budget (USD)</th>
<th>2019 Budget (USD)</th>
<th>2020 and onward Budget (USD)</th>
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</thead>
<tbody>
<tr>
<td>Phase 1:</td>
<td>Organizational and Product Development</td>
<td>$503,735</td>
<td>$547,217</td>
<td>$502,810</td>
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<tr>
<td>Visioning and strategic planning lead to a clear Action Framework with achievable goals; trust and transparent governance is ensured</td>
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<td>A comprehensive series of meetings and discussions leads to consensus around an aligned Research Agenda for the leprosy community</td>
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<td>An inclusive and broad process engages numerous stakeholders, informing a Roadmap/Toolkit for Country Capacity: assessment, visioning and menu of capacity-building options</td>
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<td>A strategy to mobilize additional resources for the aligned priorities of the Research Agenda and Leprosy Roadmap/Toolkit is launched</td>
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<tr>
<td>Meetings and workshops</td>
<td>Two leadership meetings</td>
<td>$131,286</td>
<td>$77,372</td>
<td>$96,372</td>
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<td>Two workshops at WHO regional meetings, NNN and COR-NTD</td>
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<td>Two working group meetings</td>
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<td>Travel to WHO and fact-finding mission (Bihar, India)</td>
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<td>Advocacy and tools</td>
<td>Website, translation, publications</td>
<td>$45,850</td>
<td>$29,870</td>
<td>$24,200</td>
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<td>Toolkit, website, translation, publications, short videos</td>
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<td>Total</td>
<td>$687,679 (10 months includes 10% indirect and small start-up costs)</td>
<td>$661,904</td>
<td>$609,826</td>
<td>$309,702 Novartis Foundation and $300,124 ILEP</td>
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<td>$376,963 NF and $310,716 ILEP</td>
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