

Proposed Milestones and Activities:

Project Phases: Phase #1: Building the coalition and quantifying the problem to align strategies

Year 1: Q1 and Q2

Overview: Shared program indicators and efficient national governance and program management structures will be developed to ensure political, government and stakeholder support (please note we assume that the detailed global governance structure necessary to ensure aligned vision, objectives and activities for *End Child Leprosy* is completed if we are a semifinalist). Mapping and data collection to inform planning will be conducted, and a national plan for PEP will be finalized and implemented. A peer-to-peer support network of persons affected by leprosy will be developed, along with a public education campaign. The GPZL’s network will be used to amplify and share program progress and to ensure that best practices are integrated into program operations and add value to the leprosy community and other neglected tropical disease elimination activities as a whole.

Key milestones:

Milestone 1. Shared indicators are established and adopted for program impact and performance, to be used across all countries and partners to measure the 5-year impact targets of program success.

Milestone 2. A country-specific *End Child Leprosy* working group ensures aligned vision, strong management, program monitoring, and stakeholder support for PEP implementation.

Milestone 3. National and sub-national mapping and data collection is completed and analyzed to inform decision-making on cost-effective, targeted action.

Milestone 4. Informed by Milestone 2, a five-year PEP implementation plan is developed with full stakeholder participation and support. Such plans include training, logistics and drug supply.

Milestone 5: Associations of persons with leprosy have developed a peer-to-peer support network and public education strategy to decrease stigma in the 8 *End Child Leprosy* countries.

Milestone 6. Broad national and international support for *End Child Leprosy* is fostered through the Global Partnership for Zero Leprosy including communications and advocacy and a forum for sharing best practices so that they add value to leprosy elimination and other NTD efforts globally.



Milestone 1. Shared indicators are established and adopted for program impact and performance, to be used across all countries and partners adopting the 5-year impact targets of program success.

Activities:

- 1.1 Establish a global *End Child Leprosy* independent technical advisory group to establish standardized program indicators for program impact and performance to be used in country plans and the 5-year impact targets of program success across countries.
- 1.2 Provide technical support to integrate the standardized program indicators for program impact and performance as required.
- 1.3 Monitor *End Childhood Leprosy* progress annually to advise across programs and highlight successes.

Milestone 2. Country-specific ‘End Child Leprosy’ working group ensures aligned vision, strong management and stakeholder support for PEP implementation.

Activities:

- 2.1. Led by the national Ministry of Health with support from the Global Partnership for Zero Leprosy (GPZL), form an *End Child Leprosy* task force or working group in each country and includes NGOs, persons affected by leprosy, technical experts, WHO and others.
- 2.2. As part of this, formalize the role for organizations of persons affected by leprosy in all aspects of the leprosy program including clinical, policy, advocacy, public education, and research.
- 2.3. Sign and publicize formal commitments from governments and partners aligned with the program goal.
- 2.4. The leadership team of the *End Child Leprosy* task force or working group will appoint a Technical Advisory Committee to review protocols or scientific standards for PEP implementation and ongoing monitoring data for adaptation in real time.
- 2.5. The task force or working group will meet bimonthly or more frequently as required, to finalize and govern its plan, and to review mapping, planning and data collection results as they are completed.

Milestone 3. National and sub-national mapping and data collection is completed and analyzed to inform decision-making on cost-effective, targeted action. Q2.

- 3.1. Conduct mapping to identify areas of ongoing transmission or risk to prioritize program activities.
- 3.2. Complete capacity assessment of government, ILEP members' and other relevant stakeholders.
- 3.3. Conduct a baseline survey of stigma.

Milestone 4. Informed by Milestone 2, a five-year PEP implementation plan is developed with full stakeholder participation and support. Such plans include training, logistics and drug supply. Q3

- 4.1. Convene a multi-day stakeholder meeting to develop five-year PEP implementation plan, tied to the WHO goal of zero child cases by 2030, that includes health worker training, logistics, drug supply, advocacy and other needs specific to each country. The plan will include key milestones, activities, evaluation framework and governance to ensure successful uptake of PEP.
- 4.2. Use the national PEP plan to complete an MOU (or equivalent) between stakeholders, and between stakeholders and government. Fully integrate implementation plans with ministries of health to increase sustainability and leverage existing investments.
- 4.3. Develop and establish national leprosy awareness campaign as appropriate to the country context to include in the country plan.
- 4.4. Vet country plans across stakeholder groups within countries. Ensure local engagement in program development, and health care workers in developing PEP training materials.

Milestone 5: Each of the 8 *End Child Leprosy* countries established a peer to peer support network and public education strategy to decrease stigma.

- 5.1. Identify and formalize partnerships with organizations of persons affected by leprosy (Organizations) for each country based on factors including number and location of endemic areas, language, culture, capacity, resources, sustainability and transportation.

5.2. Assess organization's partners and capacity for communications; budget management; project development, implementation; data collection; and evaluation. Identify methods and partnerships necessary to address gaps.

5.3. Identify local leader(s) in endemic areas of country and educate Organization and local leaders on PEP and goals surrounding stigma reduction.

5.4. Assess peer-to-peer support networks, if any, in endemic areas of country. Develop preliminary model to implement or expand peer to peer support networks in endemic areas of country including video-conferencing among Organizations to discuss formation/strengthening of support network.

5.5. Develop print and audio-visual materials for persons affected by leprosy and recipients of PEP for use in programs by organizations including those of persons affected by leprosy. Produce language and image guidelines for all printed and audiovisual materials that portray people with dignity, reflect that treatment is successful, are culturally appropriate and reach people of varying literacy levels.

5.6. Formulate public education strategy to include one large scale awareness rally on internationally recognized day (World Leprosy Day or International Day of Dignity and Respect developed by IDEA) and one community based program. As part of this,

5.7. Link and network organizations among all 8 countries via GPZL/IDEA social media and web site to share materials, learnings and experiences.

Milestone 6. Broad national and international support for *End Child Leprosy* is fostered through the Global Partnership for Zero Leprosy including communications and advocacy and a forum for sharing best practices so that they add value to leprosy elimination and other NTD efforts globally. Q1

6.1. Monitor progress toward *End Child Leprosy* in 8 countries and provide regular update on the GPZL website and through social media and partners. The Technical Advisory Committee will review program data quarterly and provide guidance to the program. Information can also be shared across sites, providing insights and lessons learned.

6.2. Promote *End Child Leprosy* initiatives and progress through the GPZL website and social media channels, and those of partners, in partnership with government officials.

6.3. The GPZL will implement a partnership strategy for each country Zero Child Leprosy partnership that includes aligning its members, leveraging contributions, and bringing new partners (bilateral donors, etc.) to the table.

Phase #2

Implementation: rolling out what works

Years 1 (Q 3 and 4), 2, 3, 4 & Q1-Q2 of Year 5

Overview

Efficient national governance and program management structures based on shared indicators will be fostered to ensure political, government and stakeholder support. Mapping and data collection to inform progress toward indicators will be conducted. PEP will be implemented in 8 countries to ensure more than 20 million persons at risk will receive preventive treatment. A peer-to-peer support network of persons affected by leprosy, along with a public education campaign, will empower persons impacted by the disease to become a movement to support newly diagnosed persons, educate communities about leprosy and advocate for human rights and inclusion. The Global Partnership for Zero Leprosy's network will be used to amplify and share program progress and to ensure that best practices are integrated into program operations and add value to the leprosy community and other neglected tropical disease elimination activities as a whole. Programs will be actively monitored; best practices and innovations will be shared and learning outcomes implemented across programs.

Key Milestones

Milestone 1. Enthusiastic and aligned political and stakeholder support for PEP implementation in each of 8 countries through national End Child Leprosy working group and its stakeholder engagement. Ongoing.

Milestone 2. National and sub-national mapping and program data, including for stigma, are routinely collected, analyzed and used to inform decision-making and programmatic adjustments. Ongoing.

Milestone 3. PEP is implemented in 8 high-endemic countries; over 20 million persons receive PEP by the end of Q2, Year 5.

Milestone 4: The global community of persons affected by leprosy is empowered to support newly-diagnosed persons and their families, educate communities about leprosy and advocate for human rights and inclusion.

Milestone 5. Progress toward *End Child Leprosy* and evaluation targets is monitored, advocated for and amplified through the Global Partnership for Zero Leprosy. Existing and new partners are aligned in support of country efforts.

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Milestone 1. Enthusiastic and aligned political and stakeholder support for PEP implementation in each of 8 countries through national End Child Leprosy working group and its stakeholder engagement. Ongoing.

Activities:

- 1.1. Quarterly meetings of national *End Child Leprosy* Working Group to monitor progress, address challenges, provide advice to the program, and engage stakeholders in evaluation and program modifications.
- 1.2. Annual meetings of the global End Child Leprosy Technical Advisory Group to review program progress across countries and support programs, best practices, and progress towards 5-year impact targets of program success.

Milestone 2. National and sub-national mapping and program data, including for stigma, are routinely analyzed and used to inform decision-making and program modification. Ongoing.

Activities:

- 2.1: Plan and conduct mapping to identify risk areas and prioritize areas for intervention with active case finding.
- 2.2: Routinely monitor program progress and report on standardized indicators to the national End Child Leprosy Working Group at least twice annually and a summary report to the global End Child Leprosy Technical Advisory Group annually.
- 2.3: Conduct stigma surveys annually to include in program monitoring and reporting to the national *End Child Leprosy* Working Group and the global *End Child Leprosy* Technical Advisory Group.

Milestone 3. PEP is implemented in 8 high-endemic countries; over 20 million persons receive PEP by the end of Q2, Year 5.

Activities:

3.1. Updating of the national plans with learnings and best practices from Phase 1 incorporated. This should include:

- National meeting to review phase 1 data and update report
- Adoption of the standardized program monitoring indicators and development of any locally appropriate additions for integration into the national plan.
- Information sharing on any program modifications
- Scale up plan and support defined and refined with budget updates
- Support and training to government officials on planning and monitoring PEP
- Ongoing health care worker training to ensure quality sustained PEP services

3.2. Successful Implementation of PEP - Zero Child Leprosy plans in 8 countries. These will include:

- Training to ensure all districts are conducting screening and active case finding
- Annual active case finding and screening of contacts of new cases. Newly identified hotspots will trigger adjustments to active case finding
- Contact screening of all cases identified in the last 5 years
- Between 25 and 50 household and social / community contacts treated per case
- In areas with a high number of cases, blanket screening in areas where it is optimal/ cost efficient.
- Partnerships with other NTD screening campaigns to ensure efficiency & reduced stigma

- Standardized protocols to manage type 1 & 2 reactions to prevent disabilities
- A registration system to monitor persons on multi-drug therapy

3.3. Monitoring to measure progress, identify challenges, and lead to modifications or innovations as needed

- Prioritized endemic districts maps and the % of districts covered by active case finding
- Number of districts where contact screening is routine for all new cases as standard
- System put in place to monitor and ensure protocols are followed with the standardized indicators
- Data collection and mapping will identify areas of weak implementation and the national End Child Leprosy Working Group will advise on program improvements/modifications
- Integrate ongoing monitoring for resistance into the health care system as a critical safeguard

Milestone 4: The global community of persons affected by leprosy is empowered to support newly-diagnosed persons and their families, educate communities about leprosy and advocate for human rights and inclusion.

Activities:

4.1. Establish peer-to-peer support networks to aid newly-diagnosed individuals, their families, and other individuals receiving PEP throughout the diagnosis and treatment process and identify and refer potential people with leprosy for treatment.

4.2. Create a replicable model for peer to peer support networks based on their experience and develop recommendations on how to sustain this.

4.3. Develop and execute a public education strategy by organizations of persons affected by leprosy to decrease stigma and promote increased social inclusion of persons through partnerships.

4.4. Build individual and organizational capacity for self-advocacy through an international leadership workshop for identified leaders from organizations of persons affected by leprosy in 8 countries.

4.5 Implement communications and advocacy campaign to reduce stigma including an awareness-raising rally for World Leprosy Day or International Day of Dignity and Respect. Evaluate all current and developing printed and audiovisual materials to ensure they meet language and image guidelines.

4.6. Implement a community based public education program (e.g. schools (primary through universities) or religious communities or community gatherings).

4.7. Identify and establish partnerships with local, national and international NGOs, government agencies, religious groups and traditional governments including those involved with children, women, human rights, education, employment, self-sufficiency, health, housing, disabilities and capacity building to promote inclusion.

Milestone 5. Progress toward Zero Child Leprosy 2030 and evaluation targets is monitored, advocated for and amplified through the Global Partnership for Zero Leprosy. Existing and new partners are aligned in support of country efforts.

Activities:

5.1. Develop and implement communications/social media advocacy strategy to communicate progress toward 5-year impact targets.

5.2. Work with countries to develop a National Leprosy Awareness Program in countries where this is requested.

5.3. Amplify and support IDEA's activities in increase community education on PEP and decrease stigma.

5.4. Develop and execute alignment strategy so that current partners and donors are aligned in support of PEP; explore additional donors to fund PEP and ant-stigma activities in additional countries using the models developed under this initiative.

5.5. Develop a dissemination strategy (with measurable targets) through GPZL to ensure that learnings are incorporated and add value to leprosy and other NTD efforts globally. Use the GPZL network and existing communications channels to foster knowledge-sharing and best practices, and to advocate for and promote *End Child Leprosy*.

Phase #3

Building on program success and mainstreaming for the future

Year 5, Q3 and Q4 & Years 5-10

Overview:

Efficient national governance and program management structures based on shared indicators will be the basis for a transition plan to mainstream activities into ongoing health programs, linking to universal healthcare and adopting/adapting MacArthur 100M&change program elements into existing structures nationally and globally. Mapping and data collection to inform progress toward indicators will be transitioned to routine surveillance platforms within the Ministry of Health. A strategy to ensure the continued funding of PEP as needed (through governments and donors) through 2030 will be implemented to ensure the goal of zero child cases by 2030 is realized. A peer-to-peer support network of persons affected by leprosy, along with a public education campaign, will continue to empower persons impact by the disease to support newly diagnosed persons, educate communities about leprosy and advocate for human rights and inclusion. The Global Partnership for Zero Leprosy's network will be used to amplify and share program progress and to ensure that best practices are integrated into program operations and add value to the leprosy community and other neglected tropical disease elimination activities as a whole. Success will be celebrated in each of the 8 countries and globally.

Key Milestones

Milestone 1. Measurement, sharing, and celebration of successful 5-year program goals and learning from program progress and experience.

Milestone 2. Based on Milestone 1, enthusiastic and aligned political and stakeholder support for continuing PEP implementation in each of 8 countries through 2030 to reach WHO goals through End Child Leprosy working group, integration into global processes, and stakeholder engagement. Ongoing.

Milestone 3. National and sub-national mapping and program data, including for stigma, continue as part of routine government surveillance, global reporting, and supporting NGO activities.

Milestone 4. PEP is integrated into routine health services at the ministry of health and is sustained through governments, NGOs and other partners, leading to zero child cases in high-endemic areas by 2030.

Milestone 5: the global community of persons affected by leprosy has become a network that supports newly-diagnosed persons and their families, educates communities about leprosy and advocates for human rights and inclusion.

Milestone 6. Progress toward *End Child Leprosy 2030* and evaluation targets and a plan to reach zero child leprosy by 2030 is developed, monitored, advocated for and amplified through the Global Partnership for Zero Leprosy. Existing and new partners are aligned in support of country efforts.



Milestone 1. Measurement, sharing, and celebration of successful 5-year program goals and learning from program progress and experience.

Activities:

- 1.1. Analysis and sharing of progress towards ending childhood leprosy demonstrating sustainable impact of MacArthur 100M&change quantified by the number of people successfully treated, earlier detection of cases with less disability, number of cases and disability averted and decreased population at risk.
- 1.2. Global celebration of progress as landmark catalyst for continued support for achieving the End of Child Leprosy and subsequent End of Leprosy.

Milestone 2. Based on Milestone 1, enthusiastic and aligned political and stakeholder support for continuing and sustaining PEP implementation in each of 8 countries through 2030 to reach WHO goals through End Child Leprosy working group and its stakeholder engagement. Ongoing.

Activities:

- 2.1. Complete development of a sustainability strategy integrated into government programs aligned with universal health care goals, as feasible
- 2.2. Plans for partner technical support are developed and agreed to and integrated into global program support mechanisms for NTDs and wider UHC.
- 2.3 Integrate the global End Child Leprosy Technical Advisory Group into existing sustained global advisory bodies sharing the experience with other programs.

Milestone 3. National and sub-national mapping and program data, including for stigma, continue as part of routine government surveillance, global reporting, and supporting NGO activities.

Activities:

- 3.1. Complete integration of mapping and program data, as part of existing government data collection systems with partner support.
- 3.2. Ensure that annual stigma data is included in program indicators and in appropriate government data collection tools.
- 3.3 Advocate for sustaining the national End Childhood Leprosy working group with transition to full national level membership and ownership.

Milestone 4. PEP is integrated into routine health services at the ministry of health and is sustained through governments, NGOs and other partners, leading to zero child cases in high-endemic areas by 2030.

Activities:

- 4.1. Transition plan through 2030 is developed that takes into consideration:
 - Integration into universal health coverage plans nationally with appropriate indicators of program impact and strength
 - Training of national leprosy program managers to take over leading roles
 - Fully integrated contact screening into the health system
 - Connection with new emerging approaches to PEP
 - Expansion of model to low/medium endemic countries to speed progression to zero leprosy

- Technical support will remain in place by ILEP members who have country presence

Milestone 5: The global community of persons affected by leprosy has become a sustainable network that supports newly-diagnosed persons and their families, educates communities about leprosy and advocates for human rights and inclusion.

Activities:

5.1. Finalize and make available through IDEA a model for community-based peer to peer support networks.

5.2. Finalize a plan for sustainability for national organizations of persons affected that may include membership dues, sponsorship from NGOs, donor support (including GPZL members) and other methods.

Milestone 6. Building on the 5-year impact on MacArthur 100 Million & Change, progress toward Zero Child Leprosy 2030, evaluation targets and a plan for the final 5 years (end game) is developed, monitored, advocated for and amplified through the Global Partnership for Zero Leprosy. Existing and new partners are aligned in support of country efforts.

Activities:

6.1. Disseminate national and cross-national results, and models and protocols for PEP implementation, for wider uptake in the global leprosy community including through the GPZL Toolkit, developed in partnership with WHO. Models will then be used to implement PEP in the remaining countries

6.2. Finalize impact evaluation and final report on the program's success and achievements, to be widely disseminated through the leprosy and NTD communities and beyond. GPZL and knowledge sharing platforms will publish reports at the end of year 5

6.3. Develop and finalize formal commitments with stakeholders to expand PEP to the remaining countries with leprosy cases to meet the goal of no child cases by 2030.