

GPZL Leadership Team Meeting 12 November 2022 | Hyderabad, India

Participants

Leadership team members and guests

- Amar Timalsina, President, International Association for Integration, Dignity and Economic Advancement (IDEA) Nepal
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Berta Mendiguren de la Vega, Board of Trustees, Anesvad
- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Deanna Hagge, Senior Research Advisor, The Leprosy Mission (TLM)
- Emmy van der Grinten, Technical Division Manager, KNCV Tuberculosis Foundation
- Faustino Pinto, National Coordinator, Morhan
- Gangadhar Sunkara, Senior Global Program Clinical Head, Novartis
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Linda Hummel, Chair of Executive Group, Leprosy Research Initiative (LRI)
- Lucrecia Vásquez Acevedo, President, Felehansen
- Mathias Duck, ILEP Panel of Women and Men Affected by Leprosy
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Programme
- Rabindra Baskota, Program Manager, National Leprosy Programme of Nepal
- Rao Pemmaraju, Technical Officer, WHO Global Leprosy Programme
- Suzan Trienekens, Coordinator, LRI
- Takahiro Nanri (Vice-Chair), Executive Director, Sasakawa Health Foundation
- Wim van Brakel, Chair, ILEP Technical Commission (ITC)

Secretariat

- Andie Tucker, Project Manager, Global Partnership for Zero Leprosy
- Bill Gallo, Secretariat Director, Global Partnership for Zero Leprosy
- Caroline Cassard, Communications Specialist, Global Partnership for Zero Leprosy
- Mondie Tharp, Project Manager, Global Partnership for Zero Leprosy

Unable to attend

- Alice Cruz, UN Special Rapporteur for the elimination of discrimination against persons affected by Hansen's disease and their family members
- Jordan Tappero, Global Health Representative

• Roch Christian Johnson, President, International Leprosy Association

Summary of Key Decisions / Action Items

- Action item LT members will nominate individuals for the chair-elect position.
- Action item The Secretariat will draft the 2023 workplan based on the input from the pillar group discussions.

Meeting Agenda

| Time | Item |
|---------|--|
| 30 min | I. Welcome and introductions |
| 45 min | II. GPZL Update 1. Zero is possible: Country Partnership reflection from Dr. Benedict Quao 2. GPZL's progress in the last six months |
| 120 min | III. Pillar group reflections Update from Country Partnership Pillar Group Update from Resource Mobilization Pillar Group Update from Research Acceleration Pillar Group Pillar group governance questions |
| 60 min | IV. 2023 Work plan and budget |
| 30 min | V. Governance |
| 30 min | VI. Closing / Any other business |
| | |

Meeting Notes

| Meeting Objective | Notes |
|-------------------|--|
| GPZL Update | "Zero is possible" - Reflection from Dr. Benedict Quao Question: In what way can perspectives such as those of Health Anthropology be used to learn about Health-seeking behavior or therapeutic adherence? |

• Question: How can we ensure that we do not duplicate work, especially with regard to data collection in the countries? A common complaint from countries is that each partner requires different indicators.

GPZL progress

- What part of the MERLA work remains incomplete?
 - There are two pieces of MERLA: 1) Countries measuring the impact of their action plan, and 2) GPZL implementation of MERLA to measure GPZL's efficacy. We will work with the pillar group to finalize the KPIs for both and start implementation in 2023.
- How are the views of the organizations of persons affected represented in the NTD Advocacy Project?
 - The Secretariat met with Amar Timalsina and Mary O'Friel of IDEA International to discuss the knowledge areas that we have included in the curriculum. We will pilot the project with advocates in the leprosy community.
- The high-level advocacy meeting in Côte d'Ivoire took place in June. What is the impact we see now?
 - Developing the steering committee for the national partnership has been a challenge and is still underway. The high-level meetings will look different in each country.

Pillar Group Reflections

Country Partnership Pillar Group

- ILEP partners expect GPZL to take on new country partners in 2023.
- We should keep revisiting the WHO Skin NTD framework
- How can GPZL support the implementation of action plans?
 Implementation is more important than creation. We need a country-based strategy for each country.
- What are the costs of implementation? The gaps between resources needed and what is present in our partner countries are huge, far beyond the GPZL budget.
- How can we ensure that countries aren't duplicating measurements?
 Doing slightly different M&E over and over.

Advocacy and Resource Mobilization Pillar Group

- It may make more sense to divide the pillar group into two: 1) Resource Mobilization and 2) Advocacy
- Advocacy is not an objective; it's a means to achieve our objectives. Maybe
 we don't need an independent advocacy group, maybe they should be a
 part of the other pillar groups.
- Resource mobilization could be a function or division under the other pillars.

- We need strategies for advocacy, resource mobilization, and our targets. Who should we target and who should be our partners?
- What level should we undertake advocacy? Grassroots? National level?
- What can GPZL do for advocacy for persons affected by leprosy?
 - Maintain a human rights approach to our work.
 - National partnerships should accept the participation of organizations of persons affected in each country.
 - National partnership should be structured to respond to the demands of persons affected by leprosy
 - We should not only include persons affected in local partnerships but also highlight the importance of people affected.
 - Persons affected organizations should have a central role in country activities in road-mapping and action planning.
 - GPZL could support the growth of organizations of persons affected, including leadership and capacity building strengthening.
 - Mental health and social support are priorities for persons affected organizations.
 - The most important level for persons affected is the grassroots level.
 - GPZL can connect person-affected initiatives in different countries.
 - GPZL should continue to improve health systems in countries to allow persons affected to get the health services they need.
 - GPZL advocacy should center on human rights and should include mental health and social support.
 - Messages amplified should come from persons affected themselves.
 - Persons affected should be involved in our research work because they can shape our approach to research and social science research.
 - Advocacy focus should be on the implementation of national plans.

Research Acceleration Pillar Group

- We need to look at matches between countries that are interested in conducting research and in-country academic centers that have experience in that area
- Major priorities don't change quickly. They should remain until current research has delivered results.
- It would be more helpful to repeat the inventory that Nienke undertook than to redefine priorities.

- We need to figure out how to consolidate consortia from the research workshop groups
- We should learn from the research that has been done by Anesvad on wound care.
 - This would allow us to take good practices from regional work conducted by local researchers. This would include leprosy and other skin NTDs with dermatological manifestations.
 - Anesvad has learned many lessons by connecting local researchers with global funders.
- Our research concept notes should include cross-cutting concepts such as gender and disability.
- National research regulatory authorities would benefit from a guide on allocating funds (ICMR in India has funds, and GPZL could work with the WHO country offices on this).
- National research centers could also adopt our research agenda.
- How does the research work link to the countries' action plans?
 - We need all different players in place. While developing concept notes, we discuss what research site is needed to conduct the research. If we can identify research collaborators among our country partners, we can better support and stand up research capacity among our country partners.
 - As stakeholders are identified for the workshops, we include national leprosy program managers and country representatives.
 - With the concept notes, we need to make sure that all stakeholders understand what is needed and how to implement it.
 - To link with academic research centers, we need to create an inventory of research centers and their interests to best match our proposals with sites.

Work plan and budget (Breakout groups)

Country Partnerships

2023 Workplan priorities, listed in order of priority set by the pillar group:

- Ensuring that our current cohort is set up for success—this involves an
 evaluation and review plan (KPIs), determining the role of GPZL
 post-action planning, documenting lessons learned, implementing a
 methodology to monitor action planning, and looking at gaps in our
 current model.
- Explore innovative funding streams, both for specific countries and for specific activities within countries
- Ensure the involvement of persons affected in the country work, including guidelines and expectations for involvement

- Explore and potentially develop a strategy for the integration of leprosy
 with other skin NTDs/ disability/wound care. This would start by looking
 at how this could happen and what we would need to consider as
 integration occurs
- Complete country model work with remaining country partners (FSM, RMI, and Kiribati)—including strategies for moving the work forward, identifying key people to be involved, and implementing the country model
- Bringing on new country partners—determining the number of new partners and the process of selection, developing a decision matrix for the different partner approaches, expanding the country model through the online curriculum, and determining how to ensure fidelity to the model.
- Building regional capacity—through trainings on the Country Model, facilitation trainings, and cross-country capacity building
- Promotion of the Country Model—highlighting its successes and potential uses
- Most importantly, these priorities should be considered through the lens of human rights and use a human rights approach

Other considerations for country partnerships:

- Why and how do persons affected participate in the country partnership work? What guidelines already exist? Would a factsheet be beneficial for this? Persons affected need to know more about GPZL and the work that GPZL does.
- Our work should support the development of universal health coverage.
- Our work should focus on health systems strengthening because the health system is the entryway to disease elimination and a step towards ensuring human rights.

Resource Mobilization and Advocacy

Resource mobilization objectives:

- A resource mobilization plan/strategy for the global leprosy community
- Resource mobilization strategy for country partnerships
- Resource mobilization strategy for research work
- Coalition building (communications efforts) as a means to our objectives

Open questions:

- What are we raising funds for?
- Is RM its own pillar or a part of the Research Acceleration and Country Partnership pillars?
- Who mobilizes resources for GPZL operations?

What is the Secretariat responsible for?

| | Structure Convening Agenda setting Preparation Reporting to donors Coordination of resource mobilization Database? What is the pillar group responsible for? Advancing the strategy Content development Technical communicators Focus | |
|--|--|--|
| Governance | Chair Elect: LT members will nominate individuals for the chair-elect position in the coming year. | |
| Key Upcoming Dates | | |
| Next Steering Committee meeting: 8 December 2022 Next Leadership Team meeting: March 2022 | | |