

**GPZL Leadership Team Meeting**

**11 June 2022 | 13:00 - 14:30 CET**

**Participants**

**Leadership team members and guests**

- Amar Timalina, 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
- 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
- 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)
- Mathias Duck, Global Advisor, TLMI; ILEP Panel of Women and Men Affected by Leprosy
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Programme
- Rao Pemmaraju, Technical Officer, WHO Global Leprosy Programme
- Takahiro Nanri (Vice-Chair), Executive Director, Sasakawa Health Foundation
- Wim van Brakel, Chair, ILEP Technical Commission (ITC)

**Virtual Attendees**

- Berta Mendiguren de la Vega, Board of Trustees, Anesvad
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV
- Rabindra Baskota, Program Manager, National Leprosy Programme of Nepal

**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
- Roch Christian Johnson, President, International Leprosy Association

**Summary of Key Decisions / Action Items**

<p><b>Pillar Groups</b></p> <ul style="list-style-type: none"> <li>● <b>Decision</b> – The TOR for pillar groups is approved.</li> <li>● <b>Action item</b> – Share TOR with LT. LT members will select which pillar group they will join</li> <li>● <b>Action item</b> – Define roles of pillar group chairs and external parties.</li> <li>● <b>Action item</b> – Revisit whether or not we need a 4th pillar group for coordination</li> </ul> <p><b>Leadership Team Term Limits</b></p> <ul style="list-style-type: none"> <li>● <b>Decision</b> – Terms of current LT members will be extended by one year. The chair’s term will also extend for one year. The next LT Chair will be selected by March 2023. The new chair-elect will shadow the current chair for 1 year, until March 2024, and will then serve a 2-year term, which will be renewable once. The chair and vice-chair can be external candidates. They do not have to currently serve on the LT.</li> <li>● <b>Action item</b> – Develop term logs of LT members.</li> <li>● <b>Action item</b> – The Steering Committee will develop selection criteria (TOR) for the new chair-elect before the next LT meeting in November.</li> </ul>	
<p><b>Meeting Agenda</b></p>	
Presenter	Item
Bill Simmons	I. Welcome and introductions
Andie Tucker, Mondie Tharp, Caroline Cassard	II. Strategic planning discussion <ol style="list-style-type: none"> <li>1. GPZL’s progress</li> <li>2. Work of the Partnership in the next 3 years</li> </ol>
Bill Gallo	III. Resource Mobilization <ol style="list-style-type: none"> <li>1. Strategic discussion about GPZL’s resource mobilization efforts</li> <li>2. Leadership Team Positions</li> </ol>
Bill Simmons	IV. Closing/Any other business
<p><b>Meeting Notes</b></p>	
Meeting Objective	Notes
Strategic planning discussion	<p><b>GPZL’s Progress</b> See slides on country work, research, and resource mobilization and advocacy</p> <p><b>Work of the Partnership in the next 3 years → Evolution of GPZL pillars</b></p> <ul style="list-style-type: none"> <li>● If <b>research</b> moves from product development toward horizontal coordination and enabling, who is reliable for research product development? Efforts should be shared; partners do the work while GPZL ensures accountability.</li> </ul>

- While some of the work becomes more enabling and less producing, we have to ask, are the tools effective? Then, we may have to return to the production phase to revise and adapt tools.
- **Resource mobilization** has 2 foci: country work and research. Research enables the development of more tools that will support country work.
- **Country work:** How do we demonstrate that our country work is impactful? We need to distill the impacts and learnings. Country work should be contextual yet still have a universal, clear value-add.
  - We still need clear guidelines for how countries should draft a seed funding proposal.
  - We need to prioritize zero transmission (disease) because transmission leads to disability and disability leads to stigma.
  - We need to identify our role while ensuring that the actors in the field can actually implement it.
  - We need to clarify the difference between a GPZL project and an ILEP organization's project. **What do we offer?**
    - GPZL can provide a big push for governments to establish political commitments.
    - The cost estimate of activities is an added benefit of developing the Zero Leprosy Action Plan.
    - Each organization faces roadblocks. We are an association that moves everyone faster and accelerates progress.
    - We can't dictate what MoHs do, but we have to make our common goal visual and provide enough incentive to keep moving toward each milestone.
  - What is our plan to reach people who live in remote areas and are diagnosed very late? There is a lack of knowledge and lack of resources in the national programmes.
    - We should set minimal expectations for the partner countries to meet. A country that has engaged GPZL should work differently than another country. (\*Engagement may look different for the self-guided model.)
- **All pillars:** In the last 30 years there has been a lot of research on stigma and discrimination, and most were carried out by people who did not experience the disease; even with all this research, these problems were not solved. **What does GPZL offer to reach this objective of reducing discrimination and stigma?**
  - Country Model offers access to expertise and wide buy-in
  - The Country Review process measures what is happening in each country so that we can decide what activities we need. The roadmap then brings together all stakeholders within the country. Persons affected are engaged from the beginning in the core group.

**Action Framework: Small group discussions**

**General summary:** *We need to align our three pillars, ensure that we don't miss opportunities, and learn from our partner countries' feedback.*

	<p><b>Group 1:</b></p> <ul style="list-style-type: none"> <li>● The number of countries we partner with should align with the WHO reduction goals.</li> <li>● Harmonize the goals of organizations into a common communication.</li> <li>● Rebrand the Country Model not as GPZL's product, so that the countries are the champions.</li> <li>● Resource Mobilization should be conducted by countries.</li> <li>● The mandate of the UN Special Rapporteur should be funded through 2030.</li> <li>● Request for a fourth pillar: Coordination. The Coordination pillar would encompass investment cases and cross-cutting issues.</li> <li>● The collaboration model is the ideal model for the Partnership.</li> </ul> <p><b>Group 2:</b></p> <ul style="list-style-type: none"> <li>● The goal of 30 countries is too low because there are 120 WHO priority countries. The types of assistance needed will be different for high vs low-burden countries. High burden countries don't necessarily need the most assistance.</li> <li>● Monitoring should be a joint process.</li> <li>● Targets should be more specific. If tools are needed, we need to identify those tools.</li> <li>● Ensure that persons affected are included from the beginning as partners</li> <li>● We need help to identify "hidden cases" and meet the unmet needs of people who have completed treatment and are no longer counted.</li> <li>● The horizons for the 3 zeros are different; some are close while others are longer-term goals. Zero transmission (disease) will be reached before the other zeros.</li> <li>● We need additional Action Framework indicators, especially under "No discrimination." Discrimination still exists without discriminatory legislation.</li> </ul> <p><b>Group 3:</b></p> <ul style="list-style-type: none"> <li>● We should prioritize the first 30 countries in the list of 120 WHO priority countries. We should work with India, Brazil, and Indonesia, which have many resources, to ensure they prioritize leprosy work. Countries that do not need financial support could still use technical support.</li> <li>● GPZL should focus on resource building for research and process learning around lessons learned. Learnings from the Country Model implementation should be published.</li> </ul> <p><b>Group 4:</b></p> <ul style="list-style-type: none"> <li>● Is it too ambitious to achieve 15 more countries by 2025? Is 15 enough?</li> <li>● We currently operate at the coordination level and could reach the cooperation level by 2025.</li> <li>● What would dividing resources look like for us?</li> <li>● Sharing the lessons learned from country work would expedite work in other countries</li> </ul>
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	<ul style="list-style-type: none"> <li>● GPZL should be a facilitator and a voice that summarizes and shares information. How do we make sure that the terminology we use is accessible? We need to focus on our communication capacity.</li> </ul>
Strategic planning discussion	<p><b>Work of the Partnership → Pillar Groups</b></p> <ul style="list-style-type: none"> <li>● Pillar groups will not be working groups. They will help drive the work and build strategy. Objectives should be general.</li> <li>● There should be a clear chair and focal point for each group who have significant responsibility in implementation.</li> <li>● Composition of group: We may need more than 1-2 additional SMEs/stakeholders in each group in addition to the LT members</li> <li>● Missing component: Coordination to ensure that our research priorities are being addressed and funded             <ul style="list-style-type: none"> <li>○ If the Resource Mobilization pillar group needs to strategize to mobilize resources for the Country Work and Research pillars, then the Resource Mobilization group must work closely with the other two pillar groups.</li> <li>○ Careful not to silo the pillars</li> </ul> </li> <li>● Need for a committed consultant to lead the Resource Mobilization group, since the third pillar has not progressed at the same rate as the other two pillars             <ul style="list-style-type: none"> <li>○ Hire someone to landscape resource mobilization opportunities</li> <li>○ Need to be conscientious of the Secretariat’s role and the added work that accompanies the pillar groups</li> </ul> </li> <li>● LT Agendas will be driven by pillar group work; LT hears reports from each pillar group at quarterly meetings</li> <li>● At least one person affected representative should sit on each pillar group if possible</li> </ul>
Resource Mobilization	<p><b>Strategic discussion about GPZL’s resource mobilization efforts</b>  <i>Perspectives shared via video and Zoom by Rabindra Baskota, Rose Kengonzi, and Roch Christian Johnson.</i></p> <ul style="list-style-type: none"> <li>● We need to define the scope of resources. Resources include funding, human resources, access to tools, information etc.</li> <li>● We need to visually and verbally demonstrate the movement that GPZL facilitates.</li> <li>● We need to highlight our work through communications and advocacy. We should explore personal connections to diseases (Ex: Rotary and Polio), the role of Christian organizations in leprosy, and SDR-PEP as a resource accelerator.</li> <li>● Big picture: People need to understand their role in GPZL and see themselves as a part of the work.</li> <li>● We should demonstrate our success through the success of our country partners. Show donors what can be achieved when there is follow-through on the partnerships that we have begun.</li> </ul>
Resource Mobilization	<p><b>Leadership Team Positions</b>  <i>See decisions and action items in the Summary of Key Decisions, above.</i></p>

Key Upcoming Dates
<ul style="list-style-type: none"> <li>● <b>Next Steering Committee meeting:</b> 7 July</li> <li>● <b>International Leprosy Congress:</b> 8 - 11 November in Hyderabad</li> <li>● <b>Next ILEP Assembly:</b> March 2023</li> </ul>



### Additional notes from LT members

#### Ganga's notes and comments:

##### Resource mobilization

- Resource mobilization aids in implementing country action plans with optimal speed, facilitates leprosy research to next level, and supports GPZL operations (eg. Organizing various regional and international meetings to bring experts together frequently to aid 2030 mission]
- Potential sources of resources
  - Government (impact – Country implementation)
  - Private industry (eg., Google/MSFT/App/Pharma industry; impact – technology and tools for country implementation and research)
  - Charity organizations (human and monetary resources; impact – country model and research funding)
  - Academia (human resource in the form of students etc at screening camps, healthcare awareness education etc)
  - AID organizations like USAID/US-NIH-Global health (impact - research and infrastructure)
- Steps needed:
  - Estimated budget and human resource requirement by country to implement national action plans until 2025 and 2030. If we can come out with a gross estimate for the top 30 countries we are planning, it gives a great direction for us to design a strategy to implement resource mobilization efforts at National/Sub-National and Global level
  - Estimated budget and human resource for research (diagnostics, epidemiology etc) – per research area until 2025 and 2030
  - Total ideal estimated operational budget of GPZL to accomplish 2030 mission
  - In the country action plan implementation program, we have to ask the NPZL team to find out a way to pool the respective organization's resources, identify gaps and design a resource mobilization plan

##### Ideas for future pillar activities

- GPZL has already identified the need for forming and strengthening National Zero Leprosy Partnerships. We must be able to see whether we can facilitate forming NPZL in 1 or 2 countries in 2022 to understand the feasibility and challenges
- Facilitate the formation of Global Leprosy Hospital Network [in this digital world, information on medical practice, trends in cases etc can be easily shared among all the hospitals globally which address the gap that potentially would be created by the eroding experience of leprologists] **[in collaboration w/ILEP]**
- Facilitate the formation of Global Leprosy Research Network [similar to above, bring all the active and potential researchers to become members of this online network to share each other's work and identify

complementary strengths while competing in the field]. The limited funds of LRI and other funding agencies is not enough to expedite the leprosy research. **[in collaboration w/LRI]**

- Consider the formation of National registry (database) of people affected with leprosy and all these national registries to be linked as Global network of Patients affected with leprosy to bring a stronger voice on stigma, discriminatory laws etc **[in collaboration w/Sasakawa]** [while following national compliant processes]
- GPZL should assess forming APEX centers for leprosy knowledge in various regions, especially to prevent resurgence of leprosy after we achieve 2030 goals **[in collaboraiton w/WHO-GLP]**

#### **Additional opportunities for GPZL**

- GPZL presence at NNN conference in September in Nepal
  - GPZL should to initiate a task team to on how to move forward in removing one discriminatory law related to leprosy in Nepal **[in collaboration with Sasakawa]**
- GPZL should join if any member organization of GPZL is conducting National/Sub-National level activities in Brazil and India
  - See if GPZL can propose the National Zero Leprosy Partnership concept in these top two endemic countries
  - Connect with MoH at federal and state levels
- Keeping the Task Force and Gates Foundation-like organization's networks in scope, GPZL should pilot a model to partner with other NTD groups (to share resources on the field, etc.)
- Present about the Country Model at ILC: Symposia with speakers from WHO and NLPs from parter countries

#### **Faustino's comments:**

Achieving the above goals within the existing biomedical model looks impossible. Despite the developments in those themes over the years and decades, we still follow an old-fashioned structural model that focuses on pathology, where the central problem is the bacillus and the disease as opposed to the person affected. As a person affected by Hansen's disease, I can tell you that if we keep following this model without questioning it, both of us will fail, meaning both the active agents and the liabilities of this model. We can't afford to pursue a formula in which actions affecting people that have Hansen's disease follow a vertical model, namely Governments - Health System - the People. I have always believed that the best model for dealing with these issues would be horizontally, with equality and equity, that is, treating the different with equal rights.

The current biomedical model is often abusive. I have already had to intervene many times when people affected by Hansen's disease tried to speak up, question the ways they were treated while getting health services, but instead they suffered reprisals, or people tried and render them characterless. In some places, they are often convinced that what the health system offers is enough for them to take care of their physical, mental and social health. But we can no longer accept that. We no longer live segregated nor imprisoned in prison colonies. I understand that happened not so long ago and it was justifiable. But not anymore. We cannot live in prisons with no walls, no voice and no rights.

Sometimes, people will ask me why it is that I speak that way. Someone always tells me, "You cannot generalize, there are places people are treated differently, they get humanized treatment." I, for one, know that better than anyone. I have been visiting health facilities for 30 years now, but in a universe of thousands of people affected by Hansen's disease, I am unable to quantify the coverage percentage, but I am sure it is a little percentage. Bottom line, it is not

enough to solve the problem of prejudice, discrimination and stigma worldwide. The quality standard must be equivalent, giving everyone the opportunity to be treated with dignity and respect.

Many significant changes have occurred with interventions by non- governmental organizations and social movements within the government health system. I realize that they are often looked down upon, because in a way they impact the government model of dealing with public issues, but I still do not think that summarizes the discussion. We will not achieve our goals unless we understand that our greatest allies for these issues are the people affected by Hansen's disease. I have seen governments try to work on these issues, through research, books, pamphlets, lectures, but focusing solely on the health professional as the transforming agent of this reality, and it has not worked, because they forget that we own our stories and only we have the power to transform them, both personally and collectively, either in our communities or in our city, states and countries. If we are heard, if we are instructed, if we have our world filled with knowledge, without being judged, without being underestimated, working together, fighting together, Governments, non- governmental organizations and organized social movements, as a channel of promotion the inclusion of all people affected by Hansen's disease in spaces of debates and decisions, we will undoubtedly change our history, we will write a new chapter with Zero Prejudice, Zero Discrimination, Zero Stigma.