

2nd

# GLOBAL FORUM

of People's Organizations  
on Hansen's Disease



**Hyderabad, India**  
**November 6th – 8th, 2022**

# Organizer



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**DAY 1**

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## OPENING SESSION



The beginning of the Second Global Forum was mediated by **Amar Timalsina, Global Network Coordinator of IDEA International**. "I would like to request all of you to **reconsider this disease (leprosy) as a social, financial and medical one**. I strongly believe that we have been able to dispel the myths, break the stereotypes and add up the scientific temper when it comes to leprosy."

Next, **Maya Ranavare, president of APAL India**, gave a welcome speech.

Ranavare greeted especially the Chairman of the Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa, as a "great kind-hearted human".

The president of APAL India also celebrated the attendance of young leaders at the event. "I thank these young people who attend this meeting for their understanding and for bearing the difficulties. **As you all know, disabled people are coming out of their homes, on their own. And it is like a fight.**"

The opening session also featured a distinguished guest, **India's Minister of Health and Family Welfare, Mansukh Mandaviya**. The minister **praised the work of grassroots organizations, engaged in screening and reporting suspected cases of leprosy**. "A special emphasis on case detection was given to areas with difficult access, child cases and cases with disabilities."

Mandaviya also explained, through data, that the Indian government is making "every effort to ensure and provide accessible, affordable and quality healthcare to all citizens."

Finally, **Miss World Brazil Letícia Frota** and **Miss Supranational India Pragnya Ayyagari** took the stage. **Frota** explained that she is **committed to talking about leprosy** in a simple and clear way - especially for children. **Ayyagari** summed up by saying that **their role was "spread awareness as much as we can** against the stigmas of Hansen's disease".

## KEYNOTE SPEECH

The keynote speech was delivered by **the Chairman of the Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa** "I have been working in elimination of Hansen's disease for quite some time. During my battle, I have noticed that even if the patient is fully cured of the disease, he is still faced with fierce discrimination from society"

To tap into this issue, Sasakawa started to advocate for the United Nations Human Rights Council. **It took seven years for the Human Rights Council to adopt, in June 2015, a resolution aiming to eliminate all forms of prejudice and discrimination against persons affected by leprosy and their family members**, together with the publication of a set of principles and guidelines.

"I also felt that that's not enough. Therefore, **I have taken this up to the UN General Assembly,**

in New York, and have been able to **pass the resolutions unanimously voted by 193 member countries at the time.**" With this resolution in hand, Sasakawa started to travel around all parts of the colonies throughout India. The WHO Goodwill Ambassador also **talked with Dalai Lama, the Nobel Peace Prize**, which resulted in the contribution of his trust to the cause of leprosy.

"It is very important to have your voice heard by the international community because there aren't many people yet to date with knowledge of this misconception (on leprosy) that still lies in society." Sasakawa also supported the rectification of the Universal Declaration of People with Disabilities to include those with leprosy.

**"I am a strong believer that whether it is possible or not can only be achieved once you act on it. Unless we fight, we cannot bring about victory"**, he finished.



# GROUP PHOTO







# REVISITING the previous Global Forum

& brief statement of the effect that COVID-19 had on  
the activities of the People's Organizations

The gathering brought an opportunity to reflect on the legacy of the First Global Forum to the People's Organizations. As the previous event had been held in the Philippines, in September 2019, this session also included an analysis of the effects of COVID-19 on the activities of People's Organizations.

The **United Nations Special Rapporteur Alice Cruz** remembered the event as an important moment in which those present "left with so many great hopes". **"It was the first time I saw women affected by leprosy gathering together and making their own demands, producing their own statements.** That is one of the things that really need to continue."

**Kofi Nyarko, from IDEA Ghana,** also highlighted the



meaningfulness of face-to-face contact. **"It was the very first time for us, from Africa, to get together.** It was remarkable for us to know each other, share the experience and work together. **We feel we were not alone."** **Michael Chen, from HANDA,** followed the same line. **"Although the forum was only for four days, it started much earlier and its impact continues."**

Finally, **Takahiro Nanri, Executive Director of Sasakawa Health Foundation,** shared a few prospects for the Second Global Forum. Nanri stated that **the objectives of the event were twofold:** strengthening and maximizing the roles and capacities of PO's, and creating an opportunity to present with the collective voice of persons affected.

# SESSION 1

## BUILDING ON THE CAPACITY OF THE PEOPLE'S ORGANIZATIONS

The first session of the Global Forum aimed to take organizational leaderships to the stage to discuss the development and strengthening of the institutions in which they work. For this purpose, the moderator was Lilibeth Nwakaego, from Purple Hope Initiative.

Firstly, Tesfaye Tadesse, management director of **ENAPAL, in Ethiopia**, spoke. In terms of numbers, the country ranks second in Africa and fifth in the world in new cases of leprosy detected per year.

The **main challenge of capacity building faced in the last decades was constructing a headquarters for the organization**. Since 2008, that project has confronted numerous setbacks, such as a civil war, rapid and intensive price escalation, and the pandemic.

The headquarter was launched at the very end of 2019, with the fundamental support of Sasakawa Health Foundation and a "strong commitment of board members". Since then, the main office increased the visibility of ENAPAL.

What were the **lessons learned throughout this process**? Tadesse highlighted that **challenges can be an opportunity for organizations to strengthen themselves**.

"Be wise in the proper use of capacity development opportunities to address organizational and member issues." Moreover, "strong commitment, active participation and trust" are crucial to fulfilling a project.

**"Challenges can be an opportunity for organizations to strengthen."**

Tesfaye Tadesse  
ENAPAL, Ethiopia





From **Indonesia**, spoke Al Kadri Sewa, advisor of **PerMaTa South Sulawesi**. Sewa explained one of PerMaTa projects is **centered on young persons affected by leprosy**. That audience tends to feel powerless due to stigma, to hide, not accepting themselves or having stable social relationships. "And there are many people, young people affected by leprosy, who have a great potential to bring about change."

The project goal is, then, to build a new generation of PerMaTa leaders "to continue our fight against stigma and discrimination". In the beginning, the audience was located in data from Indonesian Leprosy Control Program. With the list of names and addresses, **the young persons were invited to join meetings and training**. "This was a long process. It takes a lot of time to meet regularly and numerous times", Sewa described.

Change has been taking place gradually, through the transfer of knowledge from the first groups to the following ones. "**Step by step, people increase their confidence, increase their capacities** and then become members of PerMaTa."

The groups of young leaders carry out various activities: public awareness, data collection, peer support, teaching illiterate women to read and write, and supporting elderly persons.



**PerMaTa has a project to train young leaders. "Many of them have great potential to bring about change."**

Al Kadri Sewa  
PerMaTa, Indonesia



# Presentation of results

## Group discussions:

i) What kind of capacity building is necessary for what purpose?



## SESSION 2

### INCLUSION

The second session tackled **the benefits of including persons who have experienced leprosy and ways to achieve that inclusion**. IDEA Nepal and APAL, organizations from Asia, shared good practices. The session was moderated by Joshua Oraga, from IDEA Kenya.

Aswin Kapali, from IDEA Nepal, explained the organization was established in 1998.

The **main goals of IDEA Nepal** are twofold: **advocacy and raise awareness about leprosy** and its consequences. One of the flagships of IDEA Nepal is **fostering leadership through the identification of emergent leaders - especially female ones**. Tutoring female leaders includes maximizing involvement through training, gatherings, projects, volunteering, workshops and seminars.

Kapali also reflected on the lessons learned by IDEA Nepal. According to him, multi-year projects are preferable, once "short-term ones phase out quickly".

The treasurer of IDEA Nepal further highlighted the importance of integration, the dissemination of information worldwide, the continuous expertise exchange among the actors and regular events - such as World Leprosy Day.



**IDEA Nepal fosters the identification of emergent leaders - especially female ones.**

Aswin Kapali  
IDEA Nepal

Afterward, Ramavarai Sah, from **APAL India**, took the stage to share APAL's good practices on inclusion.

The joint-secretary highlighted that, although leprosy can cause irreversible disabilities, advances in medicine mean that the disease is now completely curable. "A major obstacle is the social stigma associated with leprosy. Many affected people continue to be excluded from society."

Specifically **in India**, national laws continue to directly and indirectly discriminate persons who have experienced the disease. "Those people want to live with dignity or live without despair. They need to be included in all domains", Sah stated.

Sah developed a set of proposals in multiple axes: education, employment, participation, cultural, political and financial.



**Though leprosy is curable, "a major obstacle is the social stigma. Many affected people continue to be excluded from society."**

Aswin Kapali  
IDEA Nepal

The panelist also presented **APAL's interventions for inclusion**. Are they: **providing awareness through workshops and public meetings**; conducting conferences to persons affected by leprosy to knowledge on how to access their rights and facing exclusion; State level interaction meetings; **workshops on The Rights of Persons with Disabilities (RPWD) Act**; and social media content.



# Presentation of results

## Group discussions:

- i) What are the benefits of inclusion?
- ii) How can we achieve inclusion?



# DAY 2

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## SESSION 3 PARTNERSHIPS

On the second day, the main session aimed to discuss partnerships made by people's organizations. The **session was moderated by Mathias Duck Enns, from ILEP.** Initially, **Faustino Pinto, from Morhan Brazil,** spoke. Pinto reflected on how the Global Forum has become an instrument in the struggle for human rights and "to strengthen our entities in a transnational articulation".

Pinto also explained why partnerships are essential in Morhan history. These ties "appealed to their ability to expand building networks". And exemplified: artists, singers and misses give visibility to the cause. The field of culture is paramount to facing the structural stigma of the disease. Partnerships also include other causes dealing with stigma, religion segments, education and so on.

**"For these partnerships to work we need to support each other.** If we fight for the same goals, if we want to build a dignified and productive life in society for all, we need to work together. **The pain of my brothers and sisters affected by Hansen's disease will never be exactly my pain. But, with empathy and solidarity spirit, I can and must join them",** Pinto concluded.

**"Global Forum has become an instrument to strengthen our entities in a transnational articulation."**

Faustino Pinto  
Morhan, Brazil





From Bangladesh talked **Rabiul Islam**, representing **ALO** (Advancing Leprosy and disadvantaged peoples Opportunities Society). ALO is a national-level organization founded in 2014 for persons affected by leprosy and for disadvantaged people's well-being. Regarding partnerships, ALO works with 102 national member federations, at district and subdistrict levels; The Leprosy Mission International (TLMI); disability movements; media; universities and donators communities.

Member federations implement different activities, in cooperation with ALO. The organization also supports for strengthening their operation capacities, together with Sasakawa Health Foundation and TLMI.

**"Through partnerships, we can increase bottom-up accessibility."**

Rabiul Islam  
ALO, Bangladesh

Islam pointed out that ALO creates opportunities for the participation of its members, sharing demands and needs. ALO also draws the attention of policymakers and public opinion through TV talk shows, leprosy conferences and national strategy development.

**"Our experience has shown that, through partnerships, we can maximize resources, raise voices together and increase bottom-up accessibility.** We need more partners in government, non-government and funding agencies", Islam detailed.

Finally, ALO also won the NTD Innovation Prize 2022 for the jointly implemented intervention called "Digital Leprosy Complication Care", together with Sasakawa Health Foundation and TLMI Bangladesh. This project connected medical staff with people needing leprosy complication care, in 11 districts, during the COVID-19 pandemic. Digital care reduced hospital admission.



# Presentation of results

## Group discussions:

- i) What are the benefits of partnerships?
- ii) How can we form good partnerships?





# DAY 3

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## SPECIAL SESSION

### Panel discussion with Miss Brazil & Miss India



Pragnya Ayyagari: I got to interact with (Goodwill Ambassador Yohei Sasakawa) yesterday and I told him: you inspire me a lot. This is the kind of energy that I will need when I'm in my 80s.

**Q: How do you want to contribute to Don't Forget Hansen's Disease campaign?**

Francilene Mesquita: The campaign was very important and it was very timely. A very significant logo. We used several strategies: translated the logo to Portuguese, signed partnerships with a number of companies and government offices, drafted disclosure materials.

**Q: Is there any specific request you would like to do to Miss Brazil and Miss India?**

Jawahar Ram Paswan: I would like to request that whenever you are doing speeches please spread the awareness that you know people who are going through with this disease.

**The Special Session brought a set of questions for a group of panelists.**

Joined the round table Letícia Frota, Miss Brazil; Pragnya Ayyagari, Miss India; Jawahar Ram Paswan, Vice-President of APAL; and Francilene Mesquita, from Morhan. The meeting was facilitated by Takahiro Nanri, Executive Director of Sasakawa Health Foundation.

**Q: What kind of message do you want to convey to young people?**

Letícia Frota: I want to tell them that young people should include others in society. Regardless of who we are, we have the right to be included in society.

**Q: What is your impression of the WHO Goodwill Ambassador?**

## SIDE EVENT

### ROOM A

#### IDEA Nepal



The IDEA Nepal president, Dinesh Basnet, stated that **its primary goal is to advocate for people affected by leprosy and raise awareness** about leprosy and its consequences. "To restore dignity, replant their lost smiles on their lips and paint their lives with love, light and happiness."

For that purpose, IDEA prioritizes capacity building for its members, forms international leaders, publishes the legacy of persons affected, takes part in global leprosy conferences and offers access to livelihood.

Two **organizations from Africa**, situated in **Senegal** and the **Democratic Republic of Congo**, spoke in Room B.

**Senegalese Association for the Fight Against Leprosy and Neglected Tropical Diseases (ASCL/MTN)** is present in ten regions out of fourteen, in **Senegal**. The organization works to promote early detection of leprosy and other disabling diseases, facilitate rehabilitation of persons and **create bonds of understanding and solidarity among its members**.

### ROOM B

#### ASCL/MTN Senegal & Dameda Foundation

**Dameda Foundation**, created in 2019, is a **rare organization in the Democratic Republic of Congo that attaches great importance to persons affected by leprosy**, Neglected Tropical Diseases, psychosocial disability in children, HIV/SIDA and fights against all forms of discrimination against these people. According to its founder, Dameda Foundation focuses on sensitizing the population about leprosy, visiting and accompanying people affected and establishing partnerships in the international field, such as IDEA.

## ROOM A

### Bogra Federation & ALO

Bogra Federation and ALO came from **Bangladesh** for the Global Forum. Both organizations were **established in 2014**.

**Bogra Federation** gathers over 100 self-help groups of persons affected by leprosy and **represents over a thousand men and women**, of whom half are persons affected. The institution's main purpose is that people affected should assume active leadership roles in their communities and carry out activities for their sustainable physical, social, economic and mental well-being.

On the other hand, the Advancing Leprosy and Disadvantaged Peoples Opportunities Society (**ALO**) has a **broader projects portfolio**, which includes advocacy, capacity building and partnership development. ALO represents 102 federations, with a **total of more than 17 thousand members**.

ALO provides technical guidance for member federations on management, lobbying with governments, donor communities, and implementing Bangladesh Leprosy Control Strategy (2022-30).

In room B, two **organizations from IDEA International in Niger and Ghana** presented their work. IDEA is the first international advocacy organization whose leaders are primarily individuals who have personally faced the challenges of leprosy.

IDEA identifies, provides and facilitates leadership opportunities for people who have experienced Hansen's disease. Through these opportunities, persons gain recognition as leaders and assume progressive leadership roles within their communities, countries and internationally.

## ROOM B

### IDEA Niger & IDEA Ghana



## ROOM A

### Sasakawa India



Sasakawa India Leprosy Foundation (S-ILF), from **India**, in turn, presented a **case study of intervention in colonies to orient women to adopt small-scale livelihoods**. The public, aged between 24 and 55 yo, gathered together to be **trained in COVID-19 mask-making** using an online platform. In addition to household chores, these women produced an average of 5 thousand masks per month. They reported this part-time engagement was useful since it contributed to the overall family income.

Room B hosted **the account of the three-year partnership between two organizations in Indonesia**: PerMaTa South Sulawesi and YDTI. PerMaTa is a provincial branch of a national organization founded in 2007. On the other hand, Yayasan Dedikasi Tjipta Indonesia (YDTI) was founded recently, in 2018.

One shortcoming of PerMaTa is that most of its members do not have a University education, which stops them from carrying out management activities for the institution.

## ROOM B

### PerMaTa South Sulawesi and YDTI

On the other hand, YDTI members have management training, but insufficient staff to implement projects. Thus, the institutions have been working together to design, develop and manage projects, as well as report writing and financial tasks.

**Since 2018, PerMaTa South Sulawesi and YDTI have been gathering some achievements**, such as running a small office, arranging an efficient management staff, growing the field workforce, and becoming known in Indonesia and abroad.



## ROOM A

### Morhan

Morhan was established 40 years ago, in Brazil, by men, but also women - side by side with them. The **presentation highlighted the role of women in building the organization**. The panelist also presented historic female leaders in Morhan.

The first one was Teresinha, the founder's wife, which received six recognition awards. In 1989 and 2016, two women were elected national coordinators, respectively, Maria Aparecida and Lucimar Batista.

Batista brought to the agenda gender parity in the direction of Morhan. In **2018**, the internal debate expanded with the approach of the Brazilian Union of Women. In the same year, **a specific department for policies for women was included in the statute**.

"This whole new sector is not exclusively for the women of Morhan. It is for us women and girls affected by leprosy in the world", explains Francilene Mesquita, Policies for Women Department coordinator.

## ROOM B

### Tanzania Leprosy Association (TLA)

**TLA, from Tanzania, has been building a long journey in the field of leprosy**. The institution was **first established in 1978** by a body of health professionals. In **2008**, **TLA mandate was given to persons affected** after leprosy was declared eliminated in the country. TLA, then, closed for almost a decade and **returned to function in 2018**.

Since 2018, TLA has been working with Sasakawa Health Foundation in advocacy and awareness raising. TLA also carries 14 socio-economic projects with LUV+ Foundation.



# PROGRAM

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# 2nd Global Forum of People's Organizations on Hansen's Disease on Hyderabad, India November 6th – 8th, 2022

## DAY 1: November 6th (Sunday)

08:00-09:00	<b>Registration</b> MC (AM) : Mr. Amar Timalina
09:00-10:00	<b>Opening Session</b> <ul style="list-style-type: none"><li>• Welcome message &amp; Introduction of participants, Ms. Maya Ranavare, APAL</li><li>• Messages from distinguished guests</li><li>• Messages from Miss Brazil and Miss India</li><li>• Keynote Speech, Mr. Yohei Sasakawa, Chairman, The Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination</li></ul>
10:00-10:30	<b>Group photo / Coffee break</b>
10:30-12:00	<b>Revisiting the previous Global Forum &amp; brief statement of the effect that COVID-19 had on the activities of the People's Organizations</b> <ul style="list-style-type: none"><li>• Revisiting the 1st Global Forum</li><li>• Asia : Dr. Michael Chen, HANDA</li><li>• America : Mr. Artur Custódio Moreira de Sousa, Morhan</li><li>• Africa : Mr. Kofi Nyarko, IDEA Ghana</li><li>• Presentation, Dr. Alice Cruz, UN Special Rapporteur</li><li>• Prospects for the 2nd Global Forum, Dr. Takahiro Nanri, Executive Director, Sasakawa Health Foundation</li><li>• Discussion</li></ul>
12:00-13:00	<b>Lunch</b> MC (PM) : Dr. Zoica Bakirtzief da Silva Periera
13:00-15:00	<b>Session 1: Building on the capacity of the People's Organizations</b> Moderator: Ms. Lilibeth Nwakaego, Purple Hope Initiative <ul style="list-style-type: none"><li>• Sharing good practice 1: ENAPAL, Ethiopia</li><li>• Sharing good practice 2: PerMaTa South Sulawesi, Indonesia</li><li>• Q&amp;A</li><li>• Group discussions – what kind of capacity building is necessary for what purpose?</li><li>• Presentation of results from group discussions &gt;&gt; session 1 committee</li></ul>
15:00-15:30	<b>Coffee break</b>
15:30-17:30	<b>Session 2: Inclusion</b> Moderator: Mr. Joshua Oraga, IDEA Kenya <ul style="list-style-type: none"><li>• Sharing good practice 1: IDEA Nepal, Nepal</li><li>• Sharing good practice 2: APAL, India</li><li>• Q&amp;A</li><li>• Group discussions – i) what are the benefits of inclusion; ii) how can we achieve inclusion</li><li>• Presentation of results from group discussions &gt;&gt; session 2 committee</li></ul>
19:00-20:30	<b>Dinner hosted by Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination</b>



## DAY 2: November 7th (Monday)

09:30-10:00	<b>Registration</b> MC (AM) : Ms. Rachna Kumari
10:00-12:00	<b>Session 3: Partnerships</b> Moderator: Mr. Mathias Duck Enns, ILEP <ul style="list-style-type: none"><li>• Sharing good practice 1: Morhan, Brazil</li><li>• Sharing good practice 2: ALO, Bangladesh</li><li>• Q&amp;A</li><li>• Group discussions – i) what are the benefits of partnerships; ii) how can we form good partnerships</li><li>• Presentation of results from group discussions &gt;&gt; session 3 committee</li></ul>
12:00-13:00	<b>Lunch</b> MC (PM) : APAL representative <b>Short-term and Mid to long-term action plan</b> Facilitator: Mr. Tesfaye Tadesse, ENAPAL <ul style="list-style-type: none"><li>• Sharing the draft action plan by session committee members<ul style="list-style-type: none"><li>– Session 1 committee : To be decided with initiative of moderator.</li><li>– Session 2 committee : To be decided with initiative of moderator.</li><li>– Session 3 committee : To be decided with initiative of moderator.</li></ul></li></ul>
15:00-15:30	<b>Coffee break</b>
15:30-16:30	<b>Dialogue with Special Rapporteur Dr. Alice Cruz</b>
16:30-17:00	<b>Break / Drafting Committee meeting</b>
17:00-18:00	<b>Sharing the draft (Drafting Committee) and endorsing recommendations</b>
18:00-19:00	<b>Closing remarks</b>
19:00-20:30	<b>Dinner hosted by the Organizing Committee</b>

## DAY 3: November 8th (Tuesday)

08:30-09:00	<b>Registration</b>
09:00-10:30	<b>Special Session: Panel discussion with Miss Brazil &amp; Miss India</b> <ul style="list-style-type: none"><li>• Introduction of participants</li><li>• Remarks from Miss Brazil and Miss India</li><li>• Sharing perceptions of Persons Affected by Leprosy (Morhan and APAL)</li><li>• Remarks of Mr. Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination</li><li>• Panel discussion</li></ul> Photo
10:30-11:00	<b>Coffee break</b>

### Side event

11:00-12:00	<ul style="list-style-type: none"><li>• Room A : IDEA Nepal</li><li>• Room B : ASCL/MTN Senegal &amp; Dameda Foundation</li></ul>
12:00-13:00	<b>Lunch</b>
13:00-14:00	<ul style="list-style-type: none"><li>• Room A : Bogra Federation &amp; ALO</li><li>• Room B : IDEA Niger &amp; IDEA Kenya &amp; IDEA Ghana</li></ul>
14:00-14:15	<b>Break</b>
14:15-15:15	<ul style="list-style-type: none"><li>• Room A : Felehansen &amp; ENAPAL</li><li>• Room B : TLA &amp; NAPAL Sierra Leone</li></ul>
15:15-15:45	<b>Coffee break</b>
15:45-16:45	<ul style="list-style-type: none"><li>• Room A : APAL &amp; S-ILF</li><li>• Room B : PerMaTa SS &amp; YDTI</li></ul>
16:45-17:00	<b>Break</b>
17:00-18:00	<ul style="list-style-type: none"><li>• Room A : Morhan</li><li>• Room B : IDEA International</li></ul>
19:00-20:30	<b>Dinner hosted by Association of People Affected by Leprosy (APAL), Sasakawa-India Leprosy Foundation (S-ILF) and Sasakawa Health Foundation (SHF)</b>

India, 2022