

SASAKAWA HEALTH FOUNDATION

Monthly Report

To

Executive Director of Sasakawa Health Foundation

Title of the Report	Monthly Progress Report
Name	Mrs. Maya Ranavare
Date of Submission	4th July 2025
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1. Report on activities of APAL State-Level Bodies and APAL Leaders

- APAL's State Committee in Bihar On 2 June 2025, a significant step was taken toward improving healthcare for leprosy-affected individuals in Purnia, Bihar, with the establishment of a permanent dressing center at Bal Krishna Leprosy Colony
- APAL's State Committee in Telangana, in collaboration with local donors and well-wishers, distributed foodgrains
- Participation of APAL in NDMA Meeting on Support for Persons with Disabilities in Disasters, 4th & 5th June 2025, New Delhi
- APAL Submission of Memorandum to the Governor of Bihar for Leprosy Pension Increase.
- Advocacy Meeting with Member of Parliament Mr. Anna Saheb for the Development of Pimpri Chinchwad Leprosy Colony
- APAL State Committee visited the Moti Sagar Leprosy Ashram located in Sitamarhi, Korba.
- The APAL State Committee of Maharashtra, in collaboration with the Maharashtra Kusta PD Sanghatna Karyakarini team, convened a review meeting to assess ongoing activities and strengthen future strategies.
- The State Committee of the Association of People Affected by Leprosy in Maharashtra recently held a crucial meeting with Dr. Ramji Adikekar, the State Leprosy Officer (SLO) of Maharashtra.
- APAL's State Committee in Bihar, a dedicated team, met with Mr. Samrat Choudhary, the Deputy Chief Minister of Bihar, to bring attention to the pressing needs of persons affected by leprosy in the state.
- APAL's State Committee in Telangana, Maniyada Ramesh, APAL's State Coordinator a dedicated camp was organized at Sivananda Rehabilitation Home (SRH), Kukatpally
- In May and June 2025, supported by APAL India's national team, the Bihar Committee intensified its advocacy activities. On 2 June 2025, APAL's Bihar State Committee engaged with officials in Purnia to push for enhanced healthcare and social entitlement access for those in leprosy colonies
- As part of its continued commitment to the dignity and rights of persons affected by leprosy, the Association of People Affected by Leprosy (APAL), along with the APAL State Committee, conducted a joint site verification visit to two colonies in Delhi

- State Committee in Telangana, in collaboration with the Hill of Hope Foundation, organized a vital outreach program in Shanthinagar Leprosy Colony and Santhoshnagar Leprosy Colony.

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APAL's State Committee in Bihar On 2 June 2025, a significant step was taken toward improving healthcare for leprosy-affected individuals in Purnia, Bihar, with the establishment of a permanent dressing center at Bal Krishna Leprosy Colony. This initiative, spearheaded by the Mahanaim Healing Ministry Trust, directly benefits the 45 residents from three nearby colonies: Bal Krishna Leprosy Colony, Banmankhi Leprosy Colony, and Purnia Court Station Colony. For years, these individuals had been suffering without access to basic medical care, resulting in recurring wounds and infections. The newly established center now provides regular wound cleaning, bandaging, first aid, and essential counselling services free of charge, significantly improving the quality of life for the patients.

The realization of this centre was made possible through collaborative efforts from local leaders and organisations. Mr. Ramesh Prasad, State Coordinator of APAL Bihar, took the initiative to connect with Mahanaim Healing Ministry Trust, seeking support for the patients. Organisational backing was provided by Shri Bindesari Rishidev, along with grassroots support from Mr. Mohammad Tajemul, Mr. Bechan Rishidev, and Mr. Laxman Rishidev—representatives of the three leprosy colonies. Their joint advocacy ensured that the voices of the marginalised were heard, and the critical healthcare need was addressed. The dressing centre now stands as a testament to community-driven healthcare reform and compassionate intervention.



APAL's State Committee in Telangana, in collaboration with local donors and well-wishers, distributed foodgrains

On 5th June 2025, APAL's State Committee in Telangana, in collaboration with local donors and well-wishers, distributed foodgrains to 23 families of persons affected by leprosy at Shanthi Nagar Colony in Peddamberpet, Telangana.

APAL extends heartfelt gratitude to the generous sponsors for their valuable support towards improving the lives of people affected by leprosy. Special thanks to Mr. Maniyada Ramesh,

APAL's State Coordinator in Telangana, for his active involvement and dedicated efforts in organising and facilitating the distribution program.



Participation of APAL in NDMA Meeting on Support for Persons with Disabilities in Disasters, 4th & 5th June 2025, New Delhi

Participation of APAL in NDMA Meeting on Support for Persons with Disabilities in Disasters
4th & 5th June 2025, New Delhi

On the 4th and 5th of June 2025, the National Disaster Management Authority (NDMA) convened a pivotal meeting in New Delhi aimed at strengthening government support for persons with disabilities during disasters. The Association of People Affected by Leprosy (APAL) was represented at this important forum by Mr. Vijay Kumar, Delhi State Coordinator of APAL, who was specially invited to contribute the perspective of persons affected by leprosy.

During the proceedings, Mr. Vijay Kumar was allotted five minutes to present his views from the stage. He used this opportunity to bring national attention to the challenges faced by a large number of persons with disabilities residing in leprosy colonies (Kusth Ashrams) across India. He emphasized a critical gap in the Government of India's disaster preparedness: the absence of a comprehensive database of persons with disabilities living in these colonies, despite multiple surveys having been conducted in the past.

Mr. Kumar also highlighted the lack of dedicated shelter homes within leprosy colonies, leaving residents particularly vulnerable during natural disasters. He advocated for the development of a national policy, led jointly by the NDMA and the Ministry of Health and Family Welfare, to systematically address the specific needs of persons with leprosy-related disabilities in disaster contexts.

Key Recommendations Presented:

Provision of ulcer dressing services and the supply of essential medical materials to all persons with leprosy-related disabilities.

Appointment of trained medical dressers in every leprosy colony to ensure regular care and support.

Construction of disaster-resilient shelter homes within all leprosy ashrams to provide safe refuge in times of emergency.

In addition to physical vulnerabilities, Mr. Kumar spoke about the social stigma and economic hardships experienced by many leprosy-affected individuals. He pointed out that family rejection and societal discrimination often force these individuals to live in extreme poverty, sometimes on the streets, without access to basic services or protection during disasters. He issued a strong appeal to the Government of India to prioritise this highly marginalised group in all future disaster management and welfare programs. In his closing remarks, Mr. Kumar stated:

"Leprosy-affected persons with disabilities continue to be marginalised. I request the Government of India to ensure that they receive proper support and opportunities to live independent lives with dignity and equality in society."

Conclusion

APAL's participation in the NDMA meeting was a significant step in ensuring that the voice of leprosy-affected persons with disabilities is included in national disaster management strategies. The recommendations presented by Mr. Vijay Kumar were well-received by NDMA officials and other stakeholders. APAL will continue its advocacy efforts to ensure these crucial issues are addressed in upcoming policies and programs.



APAL Submission of Memorandum to the Governor of Bihar for Leprosy Pension Increase

APAL Submission of Memorandum to the Governor of Bihar for Leprosy Pension Increase
On 10th June 2025, APAL's State Committee in Bihar was to request the honourable Governor of Bihar, Mr. Arif Mohammad Khan, to increase the disability pension amount for persons affected by leprosy in the state.

During the visit, an official application was submitted at the Governor's office seeking an appointment to discuss the issue in person. The committee hopes to receive a call for a direct meeting soon, which will enable further dialogue and follow-up reporting on the matter.



Advocacy Meeting with Member of Parliament Mr. Anna Saheb for the Development of Pimpri Chinchwad Leprosy Colony

Advocacy Meeting with Member of Parliament Mr. Anna Saheb for the Development of Pimpri Chinchwad Leprosy Colony

The primary objective of this advocacy activity was to engage with policymakers to seek support for new house construction and improved infrastructure for the leprosy-affected residents of Pimpri Chinchwad Leprosy Colony, ensuring safe and dignified living conditions.

On 11th June 2025, as part of its continuous advocacy efforts, the Association of People Affected by Leprosy (APAL), along with the APAL State Committee in Maharashtra, met with Member of Parliament Mr. Anna Saheb in Bansuri, Pune. The meeting focused on the long-standing issues faced by residents of the Pimpri Chinchwad Leprosy Colony, particularly the urgent need for new housing development. The APAL delegation elaborated on the poor and unsafe living conditions endured by the community and emphasized the necessity of immediate action to ensure their well-being. Mr. Anna Saheb responded with empathy and understanding, assuring the delegation that he would take up the matter seriously and do the needful to facilitate the construction of new houses. His positive response brought hope to the community, reinforcing the importance of continued advocacy and collaboration with government representatives for the upliftment of persons affected by leprosy.



APAL State Committee visited the Moti Sagar Leprosy Ashram located in Sitamarhi, Korba.

APAL Moti Sagar (Sitamarhi) Leprosy Ashram Visit:

On June 12, the APAL State Committee visited the Moti Sagar Leprosy Ashram located in Sitamarhi, Korba. The ashram supports children studying up to the 11th standard through

scholarship programs, ensuring their education is not disrupted despite health challenges. During the visit, it was observed that this colony consists of 28 houses with a total of 85 residents affected by leprosy. A critical need noted was the uninterrupted availability of daily medications and ulcer care, which are essential for both children and adults to maintain their treatment regimen and prevent complications.

Leprosy Ashram, Mudapar (Korba):

Later in the day, the team visited another leprosy-affected colony in the area—referred to locally as the Leprosy Ashram at Mudapar. This community comprises 24 households with 35 individuals currently undergoing treatment. Among them, six people are affected by "pushp" (ulcerated lesions), which require immediate and focused medical attention. The APAL team emphasized the importance of establishing a consistent supply chain for daily drugs as well as dressing materials to manage ulcers effectively and avoid disability.

Community Self-Care Training at Dildar and Beldar Paras:

In parallel, APAL members conducted self-care training sessions in two nearby paras—Dildar Para and Beldar Para. These sessions covered essential practices such as daily wound cleaning, proper dressing techniques, and hygiene habits to prevent secondary infections. By empowering residents with practical self-care knowledge, the committee aimed to reduce the burden on healthcare providers and promote sustained ulcer management at the community level.

Summary of Imperatives and Future Action Plan:

The June 12 visit underscored several urgent needs across the colonies:

A stable supply of daily leprosy medication for both children and adults, especially in educational settings like Moti Sagar.

Access to ulcer care supplies, including dressings and antiseptics, particularly for the six residents with pushp.

Continued scholarship support for school-going children to link health and education outcomes.

Ongoing self-care initiatives in paras to reinforce skills and independence in managing leprosy complications.

With 85 individuals in Sitamarhi and 35 in Mudapar, making a combined total of 120 people affected, the APAL State Committee's coordinated efforts to deliver medication, education, ulcer care, and community training are vital. Sustained follow-up, resource mobilisation, and caregiver empowerment will significantly improve health outcomes and prevent further disabilities.



The APAL State Committee of Maharashtra, in collaboration with the Maharashtra Kusta PD Sanghatna Karyakarini team, convened a review meeting to assess ongoing activities and strengthen future strategies.

On 15th June 2025, The APAL State Committee of Maharashtra, in collaboration with the Maharashtra Kusta PD Sanghatna Karyakarini team, convened a review meeting to assess ongoing activities and strengthen future strategies. The session focused on evaluating the progress made in advocacy, community engagement, and service delivery to persons affected by leprosy. The meeting also highlighted the importance of streamlining coordination between APAL and the local grassroots structures to improve outreach and support mechanisms.

The team exploring how visual tools and creative media could be effectively used for awareness campaigns, stigma reduction, and training materials. Looking ahead, the Maharashtra State Committee and the Kusta PD Sanghatna team committed to expanding digital outreach, strengthening grassroots leadership, and initiating new community-based programs tailored to the needs of persons affected by leprosy. This forward-looking approach underlines their dedication to inclusion, dignity, and rights-based development.



The State Committee of the Association of People Affected by Leprosy in Maharashtra recently held a crucial meeting with Dr. Ramji Adikekar, the State Leprosy Officer (SLO) of Maharashtra.

Meeting with State Leprosy Officer, Maharashtra: Addressing Health Challenges Faced by Persons Affected by Leprosy

The State Committee of the Association of People Affected by Leprosy in Maharashtra recently held a crucial meeting with Dr. Ramji Adikekar, the State Leprosy Officer (SLO) of Maharashtra. The purpose of the meeting was to discuss the ongoing health issues encountered by persons affected by leprosy in the state and to collaboratively explore viable solutions to improve their overall well-being.

During the meeting, the APAL representatives shared ground-level realities, including gaps in timely diagnosis, irregular supply of Multi-Drug Therapy (MDT), lack of follow-up care for leprosy-related complications, and the need for increased awareness at both community and health provider levels. The team also emphasized the challenges faced by elderly PALs, including disability care, access to reconstructive surgeries, and long-term rehabilitation support.

Dr. Adikekar appreciated the concerns raised by APAL and acknowledged the need for a strengthened and more inclusive health response. He assured the team that the health department would take steps to ensure a regular supply of medicines, improve coordination with local health centers, and organize special camps for disability management and ulcer care in high-burden areas. He also expressed support for community-based awareness campaigns and collaboration with PAL-led organizations to ensure that the voices of affected individuals are central to program planning.

This meeting marked a positive step toward better state-level coordination and highlighted the importance of continuous dialogue between government health officials and affected communities to effectively address leprosy-related health issues in Maharashtra.



APAL's State Committee in Bihar, a dedicated team, met with Mr. Samrat Choudhary, the Deputy Chief Minister of Bihar, to bring attention to the pressing needs of persons affected by leprosy in the state.

APAL Bihar Team's Advocacy Meeting with Deputy Chief Minister of Bihar

To submit a request for the implementation of a leprosy pension scheme and advocate for financial support and dignity for persons affected by leprosy.

On 18th June 2025, APAL's State Committee in Bihar, a dedicated team, met with Mr. Samrat Choudhary, the Deputy Chief Minister of Bihar, to bring attention to the pressing needs of persons affected by leprosy in the state. During the meeting, the team formally submitted an application requesting the provision of a leprosy pension, aimed at ensuring a basic level of financial support and dignity for those who have long been marginalized and continue to face socioeconomic hardships due to the disease.

Mr. Choudhary listened attentively to the team's appeal and expressed genuine concern about the issues raised. He acknowledged the importance of the matter and assured the team that he would personally review the request. His response gave a sense of hope and commitment toward addressing the needs of leprosy-affected individuals in Bihar. The APAL Bihar team remains optimistic that the state government will take necessary and timely action to implement the leprosy pension scheme, marking a significant step toward inclusion, support, and justice for the affected community.



APAL's State Committee in Telangana, Maniyada Ramesh, APAL's State Coordinator a dedicated camp was organized at Sivananda Rehabilitation Home (SRH), Kukatpally

APAL's State Committee in Telangana on the on-site UDID distribution event at SRH, Kukatpally:

On June 22, 2025, under the initiative of APAL's State Committee in Telangana, Maniyada Ramesh, APAL's State Coordinator a dedicated camp was organized at Sivananda Rehabilitation Home (SRH), Kukatpally. During this event, 72 individuals affected by leprosy received their Unique Disability ID (UDID) cards on the spot. The fully inclusive camp covered enrollment, card generation, and handover, ensuring that beneficiaries obtained this critical government-issued documentation directly, without having to navigate external bureaucratic processes.

Empowering Through Identity Documentation

The UDID card serves as a universal, officially recognised disability certificate under the Rights of Persons with Disabilities (RPwD) Act, 2016. Replacing older certification formats, it holds nationwide validity and standardises identification, affirming each individual's dignity and rights.

Facilitating Access to Welfare Benefits

A central aim of the event was to facilitate access to essential welfare schemes. Once equipped with a UDID card, recipients can more efficiently claim government aid such as pensions, travel concessions, healthcare subsidies, assistive devices, and educational or vocational support. Eliminating bureaucratic delays empowers beneficiaries to access services seamlessly, boosting healthcare access, social inclusion, and livelihood prospects.

Projected Long-term Impact

With 72 individuals now equipped with official identification, the event marks a powerful stride toward dignity, empowerment, and equality. The UDID cards are more than documents—they are tools that help reduce stigma, promote independence, and foster equity. Over time, these cards will serve as gateways to services and full societal integration.



In May and June 2025, supported by APAL India's national team, the Bihar Committee intensified its advocacy activities. On 2 June 2025, APAL's Bihar State Committee engaged with officials in Purnia to push for enhanced healthcare and social entitlement access for those in leprosy colonies

APAL's advocacy in Bihar and the recent government action:

APAL's State Committee in Bihar has consistently stepped up its intervention at both block and state levels. A prime example is its proactive push in early 2024, when the committee formally petitioned authorities on behalf of leprosy-affected individuals in Motihari Colony whose disability pensions had been discontinued

This action, led by activist Mr. Ramavarai Sah, ensured the reinstatement of pensions and showcased APAL's strategic use of direct engagement with government officials.

Beyond individual cases, APAL has engaged in extensive advocacy across leprosy colonies. On 13 March 2024, the State Committee's delegation visited Banmankhi Colony in Purnia to highlight dire living conditions: families dwelling in plastic-sheet huts on land without legal tenure

They submitted memoranda calling on authorities to secure land rights, urging remedial action to stabilize housing and support among colony residents.

In May and June 2025, supported by APAL India's national team, the Bihar Committee intensified its advocacy activities. On 2 June 2025, APAL's Bihar State Committee engaged with officials in Purnia to push for enhanced healthcare and social entitlement access for those in leprosy colonies

Then on 26 May 2025, they held a high-level advocacy meeting—with senior leaders present—to press the state government on disability pension entitlement issues

These efforts ultimately yielded tangible results: Bihar's Social Security Pension Scheme was officially revised, boosting monthly pension—previously ₹400—for persons with disabilities (including those affected by leprosy) to ₹1,100. The new rate, set to take effect from 1 July 2025, was announced by Chief Minister Nitish Kumar ahead of the upcoming state elections

Thanks to APAL's sustained block-to-state advocacy, many affected individuals will now receive a nearly threefold increase in financial support—an essential lifeline for those living in poor conditions within leprosy colonies. The upcoming July announcement marks a significant milestone in ensuring better social entitlement access for this vulnerable community.



Nitish Kumar

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मुझे यह बताते हुए खुशी हो रही है कि सामाजिक सुरक्षा पेंशन योजना के तहत विधवा महिलाओं, वृद्धजनों और दिव्यांगजनों को अब हर महीने 400 रु० की जगह 1100 रु० पेंशन मिलेगी। सभी लाभार्थियों को जुलाई महीने से पेंशन बढ़ी हुई दर पर मिलेगी। सभी लाभार्थियों के खातों में यह राशि महीने की 10 तारीख को भेजना सुनिश्चित किया जाएगा। इससे 1 करोड़ 9 लाख 69 हजार 255 लाभार्थियों को काफी मदद मिलेगी।

As part of its continued commitment to the dignity and rights of persons affected by leprosy, the Association of People Affected by Leprosy (APAL), along with the APAL State Committee, conducted a joint site verification visit to two colonies in Delhi

Joint Site Verification Report: APAL & State Committee Visit – Delhi

As part of its continued commitment to the dignity and rights of persons affected by leprosy, the Association of People Affected by Leprosy (APAL), along with the APAL State Committee, conducted a joint site verification visit to two colonies in Delhi: Lok Mata Kushtha Ashram in Anand Parvat and Shalimar Leprosy Colony. This visit, led by APAL Vice President Shri Jawaharlal Ram Paswan, APAL Jharkhand State Leader Shri Madhusudan Tiwari, and local guide Shri Arjun Ram, aimed to assess the living conditions, infrastructural gaps, and urgent needs of the residents.



1. Lok Mata Kushtha Ashram, Anand Parvat

Inspection Date: 16 June 2025

Total Families: 43

Land Ownership: Delhi Development Authority (DDA)

Colony Pradhan: Mrs. Jaya Reddy

The inspection revealed critical issues affecting the well-being of residents. The colony was found to be submerged in rainwater, with water stagnating inside homes and toilets—creating serious sanitation and health risks. Drinking water was found to be impure, increasing the vulnerability of already at-risk residents. Moreover, 10 families have been unjustly removed from the official house list, causing deep distress and exclusion from housing benefits.

This flooding and health hazard occur repeatedly every year, yet the colony remains neglected. APAL recommends a permanent drainage system, reinstatement of the 10 excluded families, elevation of water pipelines, and inclusion of the colony in the PMAY housing scheme to ensure long-term relief.

2. Shalimar Kushtha Colony

Inspection Date: 19 June 2025

Total Families: 10 (including 4 leprosy-affected families)

Land Ownership: DDA

The second visit to Shalimar Leprosy Colony exposed an even more alarming situation. The colony comprises kutchha houses with no drainage, no toilets, and a critical shortage of water, especially during summer. The families are completely deprived of all government schemes, and social tension prevails due to the cohabitation of leprosy-affected and non-affected families under the same roof.

The colony head expressed helplessness:

“We are facing many difficulties here, but no solution is being found.”

Given the small size of the colony and the lack of facilities, APAL strongly recommends relocating these 10 families to a nearby, better-equipped colony. This would ensure access to basic services and government schemes. A rehabilitation plan should be developed by DDA/NDMC, with APAL involved in monitoring the relocation and dialogue process to protect the rights and dignity of the residents.

Conclusion:

The conditions in both colonies reflect a serious denial of basic human rights, social dignity, and essential public services for persons affected by leprosy. These long-standing problems have remained unresolved for years. APAL India strongly urges the relevant departments, particularly DDA and NDMC, to take immediate and coordinated action to address the needs of these vulnerable communities.



Medical Support and Relief Distribution Drive at Shanthinagar and Santhoshnagar Leprosy Colonies,

On 26th June 2025, APAL's State Committee in Telangana, in collaboration with the Hill of Hope Foundation, organized a vital outreach program in Shanthinagar Leprosy Colony and Santhoshnagar Leprosy Colony. This collaborative initiative focused on extending medical support and supplies to 150 persons affected by leprosy, who live in marginalized and underserved conditions.

The APAL State Committee facilitated the coordination between the community members and the Foundation, ensuring that the materials reached those most in need. The supplies included basic medicines, wound care kits, protective footwear, and hygiene items specifically designed to aid in the long-term care of people with leprosy-related disabilities.

This effort reflects APAL's ongoing commitment to health equity and dignity for persons affected by leprosy. Through such partnerships, the organisation continues to strengthen its grassroots presence.



Maya Ranavare
President APAL