

NEWSLETTER

Association of People Affected by Leprosy

Equity and Integration

Private Circular Only

First Edition

Jan to Mar 2020



Background

National Forum India formed by and for the Persons affected by leprosy across the country and it was started informally in 2006. This initiative helped to have a networking with the leprosy colonies. A National Conference on Integration & Empowerment of people affected by leprosy was conducted in New Delhi in 2005 and 2006 which helped to unite the people affected by leprosy from various parts of the country. National Forum India was registered in Feb. 2011. National Forum India is patronized by Mr. Yohei Sasakawa, WHO Goodwill Ambassador for the Elimination of Leprosy & Chairman of The Nippon Foundation (TNF). The founder & senior consultant of National Forum India is Dr. P. K. Gopal, who received Padma Shri Award for his relentless service in the leprosy field for the past 48 years. Colony Details: A National survey of leprosy colonies was conducted and identified around 800 leprosy colonies across in India including Self settled Colonies, NGOs supported colonies and Rehabilitation homes etc., Several Socio Economic Empowerment Workshops were conducted all over India. Self-Settled Colonies of affected persons had elected State leaders and State teams in 19 major states. The empowerment workshop helped State leaders and colony leaders to work for improving the quality of lives of affected people to live with dignity without stigma and discrimination.

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Aims and Objectives

- To work for the socio –Economic Empowerment and welfare of persons affected by leprosy and their families and physically disabled persons.
- The objectives of ASSOCIATION OF PEOPLE AFFECTED BY LEPROSY are to promote respect and dignity in the lives of those who have been affected by leprosy and persons with disability to work in partnership to ensure that they live are awarding life with dignity.
- To associate with government, non-government organizations and international agencies for uplifting the social and economic conditions of people affected by leprosy and physically handicapped.
- To provide education to the community about leprosy, general health, and environment
- To collect information from various sources on the subject of leprosy and physically handicapped in India and to function as a consulting agency
- To combat prejudice, discrimination, segregation, rejection, the use of derogatory terminology and the stigma associated with leprosy through self-support, self reliance, dignity and public health awareness programmes.
- The income and funds of the society be solely utilized towards the objects of the society and no portions of it shall be utilized for payments to members by way of profits, interests etc.
- The benefits of the society shall be open to all persons irrespective of caste, religion, creed, sex etc.
- The association of people will represent the people affected by leprosy and enable the people in the states to become autonomous and strong in working for the empowerment of people affected by leprosy

Message from WHO Goodwill Ambassador Mr. Sasakawa



I am delighted that the Association of People Affected by Leprosy (APAL) is launching a newsletter through the efforts of Chairman Narsappa and Vice- Chairman Venu Gopal.

Established by Dr. P. K. Gopal in 2006 as the National Forum India. APAL is India's first national organization of persons affected by leprosy and has worked actively in cooperation with organizations such as The Nippon Foundation and Sasakawa-India Leprosy Foundation to restore the dignity and independence of persons affected.

Through the formation of networks among the 750 or more leprosy colonies across India and the emergence of leaders among people affected. APAL has achieved significant results through negotiation with the Government, such as increasing the size of pensions and improving living conditions in the colonies. Also, this year, amid the Corona virus pandemic, APAL has played an active role in the provision of food and other emergency assistance to colony residents across India. APAL is now one of the world's leading examples of a successful organization of persons affected by leprosy.

To accelerate efforts to achieve self- reliance and dignity, it is more important than ever to communicate what APAL is doing as well as the voices of those it represents. I hope that this newly-launched newsletter will become one of the pillars to disseminate this information.

I am convinced that as more people encounter and appreciate the wonderful work and achievements of APAL, this will contribute to improving the lives of persons affected as well as spreading a correct understanding of leprosy.

Message from Founder President



Dr. P.K. Gopal

I am happy to know that APAL – Association of People AFFECTED BY Leprosy will launch a quarterly Newsletter.

A Newsletter is a short written report that tells about the recent activities of an organization and that is sent to many individuals and organizations. I learnt that APAL will dispatch the Newsletter online.

India has the largest number of persons affected by leprosy in the world. Communication or a network among the persons affected by leprosy in India was initiated by the National Forum of India which was established and managed by persons affected by leprosy. Workshops on Social and Economic empowerment of affected persons conducted in many states through which the State Leaders were elected by the people. The name of the National Forum was changed as APAL. The State Leaders are assisted and guided by APAL to implement various programs for the development of the affected people. APAL work with Sasakawa India Leprosy Foundation in improving the living conditions of affected people who live in 760 leprosy colonies. Government of India is working to contain and eliminate leprosy from India. APAL work for the non-medical issues especially to eliminate the stigma and discriminations in leprosy through various programs. It closely works with ILEP member NGOs and Government. I believe that the News Letter will help to disseminate its activities and thus enable the affected people to be strong in improving their living conditions.

Activities

- Socio economic empowerment of People affected by leprosy and their families
- Grass root level programs for colony leaders and people
- Networking among colonies
- Strengthening of State Leaders & Team of colony members for effective working in the states.
- Women & Youth Empowerment workshops
- Capacity Building Training programs for state leaders, colony members & Youth
- Human Right Redresses Cell.
- Special program for disseminate message of Global Appeal.
- Work with the Government, WHO, NGOs”, National & International agencies for mainstreaming of people

Outcomes

- Petition was filed before Rajya Sabha Petition Committee of Parliament and the Government has taken action on the recommendations of the committee.
- Civic amenities are being provided to leprosy colonies on the intervention of Human Right commission.
- More than 90% cases were referred to Human Right Commission and were decided in favor of people affected by leprosy.
- Public Interest Litigation (PIL) APAL was submitted to Supreme Court of India, seeking amendments in the provisions of the derogatory Acts.
- Odisha State Government amended Local Panchayat Election Act.
- People affected by leprosy are being invited by the Government for decisions making in leprosy related policies and programs.
- WHO has published guidelines on strengthening participation of people affected by leprosy services; these guidelines were translated by APAL in Hindi language.
- APAL published, UN P&G on elimination of stigma & discrimination faced people affected by leprosy & their families

Ulcer Dressing Unit



To facilitate the 250 ulcer suffering patients, APAL through its MP State Committee Sahyog Kusht Nivaran Samiti has applied under CRS scheme to Morya Saria Industries. On 5th, January, 2020 Mr. Pawan Singania, M. D. of Morya Saria inaugurated the first dressing unit at Arunodaya Leprosy Colony, Indore. MP.

Food Grains support



Mr. Ghasi Ram, State leader of Chhattisgarh contacted a local donor for food grains support at Raipur and distributed to 60 families of people affected by leprosy at Mora colony while the COVID-19 lockdown.



Delhi State leader Mr. Giridhar Lal and committee members are distributed food grains to 50 families of people affected by leprosy at Tahirpur colony; sponsored by the Government of Delhi.

Message from the President



V. Narsappa

As a President, I am very pleased and proud to make public the Newsletter, first edition because I got an opportunity to share our (APAL) vision and activities. I want to convey my gratitude to all of you who have supported us for this happened. I never forget the dedicative service of the greatest personalities who are functioning for people affected by leprosy specially Mr. Yohei Sasakawa, Chair Person, Nippon Foundation, Dr. Nanri Taka, CEO, Sasakawa Health Foundation, Dr. P. K. Gopal, founder president of APAL, Mr. Venu Gopal Vice president of APAL, the dedicative personality Mr. Uday Thakar, advisor of APAL, Board members, the state and the colony leaders and people in the earlier past, and present, for the affected people's empowerment and development to live with assurance and dignity and stand on our own feet. Indeed, the organization of APAL formed for the rights of people affected by the disease of leprosy, predominantly those who reside in the leprosy colonies. The APAL always working for people affected by leprosy and their families who lost their livelihood due to leprosy related stigma and discrimination, suffering from disability visibly and non-visibly; The APAL's platform is very good to us and our people to raises their voices for our needs and also the essential needs of our community. As a person affected by leprosy I experienced much leprosy related stigma and discrimination in many places. All the people affected by leprosy experienced the reason for stigma in society is appropriate to less awareness of the disease of leprosy, poor financial status, and illiteracy. I can say now that situation was slightly changed better than before. From this newsletter, I request all of you that we want your support to APAL to work for empowerment of people affected by leprosy.

Message from Vice President



G. Venu Gopal Naidu

Association of People Affected by Leprosy was established and managed by people affected by leprosy of India to bring about a sustainable change in the economic and social value of our brothers and sisters living in 760 self-settled leprosy colonies across India. It's fighting against stigma and discrimination prevailing in society towards leprosy and leprosy affected persons to regain dignity. On the other hand, it's trying hard to provide vocational and higher educational opportunities for the children & for self-reliance of affected persons in collaboration with NGOs Sasakawa India Leprosy Foundation, Rising Star outreach India, etc. I feel proud to mention here that due to continuous efforts, APAL is attaining achievements to bring changes in the living standards of people affected by leprosy and heading towards its goal to join the mainstream of the society. By joining the NLEP programs of the Government of India, APAL is also contributing its services for leprosy elimination to make leprosy free India. I know it's a long way to reach the goal but believes where there is a will, there is a way. I am pleased to endeavor to launch the newsletter 1st quarterly edition of APAL to disseminate information about the successful activities conducting by APAL towards the social and economic empowerment of people affected by leprosy families. I am much regard to Mr. Yohei Sasakawa, Chair Person, Nippon Foundation, Japan for his inspiration and moral support & to Dr. Nanri Taka, CEO, Sasakawa Health Foundation for his contributions. I also thank to Dr. P. K. Gopal, consultant, Mr. Uday Thakar, advisor for their services. I also appreciate our State Committee leaders who are doing an excellent job for the upliftment of the affected families of their respective states. I also appreciate Mr. Narsappa, President to lead our people successfully and also our APAL board members for their services & the office staff for their qualitative performance to run APAL. I look forward to APAL's continued expansion to strengthen our families of people affected by leprosy.

Book Unveiling



Mr. Sasakawa has written a book named "No matter where the journey takes me". Unveiling by Hon'ble minister Mr. Jayshankar. Mr. Tarun Das, Dr. Vineetha Shankar, and Dr. P. K. Gopal are participated.

Mr. Sasakawa Gujarat



Mr. Y. Sasakawa, Mr. Nanri, Ms. Kiyomi, Mr. Venu Gopal, Mr. Uday Thakar, Dr. Rashmi Shukla WHO, Ms. Megha Ben and Gujarat state leaders met Disability Commissioner Mr. B.G. Nival at his office; also met Chief Secretary Health Ms. Jayanti Ravi. The team submitted memorandum to Disability Commissioner and Chief Secretary for land patta issues. They have assured will take necessary action for people affected land pattas.

Women's Day Celebrations

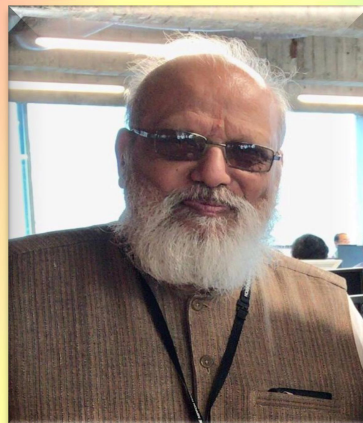


Ms. Maya Ranavare-Treasurer of APAL participated in the Women's day celebrations at Trombe Leprosy Colony Mumbai. The Local ward counselor and 50 women are participated. They honored the best social workers in the leprosy colony.

World Leprosy Day Celebrations



Message from Advisor



Mr. Uday Thakar

It is a pride movement for APAL, as APAL is releasing the first newsletter, since its formation, APAL is working for the people, by the people with people. It has provided common platform to people affected by leprosy to share their feelings, experiences and problems. In last 10 years numerous problems has been identified. APAL has taken keen initiative to solve these problems. APAL has successfully developed the leadership among people affected and made them aware about rights and duties. I am sure that, this newsletter will take the efforts of APAL to the civil society, which will result in reducing leprosy related stigma and discrimination. My best wishes for this new project.

Meet the Govt. authorities



Mr. Rasul Mulla State leader Maharashtra, Ms. Maya Ranaware- APAL Treasurer and other Mumbai leprosy colony people met with Honorable Minority Minister and Foster Minister Mr. Navab Mallik had discussed the problems of Leprosy colonies.

Case Study of Mrs. Sathya



“When my disease appeared, immediately my relatives disappeared”

Born in 1990, Sathya was affected by leprosy (type II reaction) at the age of 14; her mother was also affected by leprosy; Sathya always stayed with her mother until her mother died due to leprosy in Chengalpattu, Tamil Nadu. After 2 years, Sathya who was afflicted with ulcers and wounds, started to face discrimination at her grandfather's household; They hid her indoors and gave her a separate outhouse; they kept her alone and lonely and they even separated plates and glasses for her; they always told her “you are too dangerous and you will certainly kill us with your disease and curse like your mother”. She experienced much leprosy related consequences at the physical, social, and most of all at the psychosocial level. Here's her testimony.

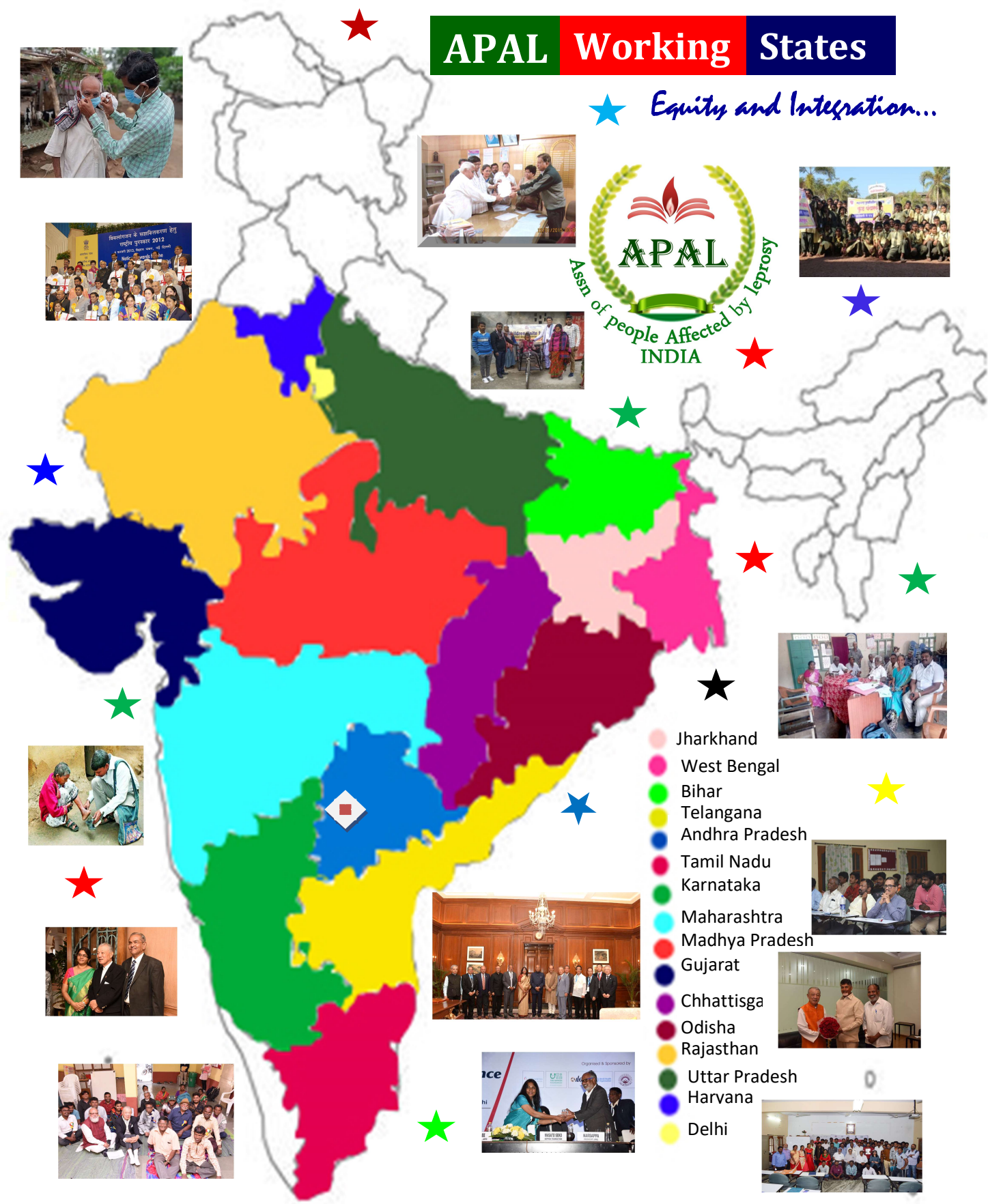
I was 12 years old and was staying with my mother at the leprosy hospital CLTRI (Central Leprosy Treatment and Research Institute) due to my mother's treatment of leprosy; she had multiple complications and died right in front of me at the hospital of CMC (Chengalpattu Medical College). When I was 14 years old, I started to get small wounds on my foot and my grandfather discovered I had leprosy just like my mom. From that day on, they isolated me for one year and told me “you can go from here if you wish to save us from death.” One day I went into the hospital where my mother was treated and there, I finished a one-year MDT course.

When I was discharged from the hospital, I met a man at the railway station. He took me to a safe place and after a few days, I got married to him and had one boy child. He pushed me away when the signs of leprosy became visible; In the same way, I was cheated by others in legal matters for 3 times in issues related to my 3 years child, and influenced by people's suggestions I gave my child to a woman for adoption due to my inability and disease of leprosy and I went back to the hospital to treatment for leprosy reactions. That particular time was very crucial in my life because I lost my child and had wounds appearing in my entire body, even in my mouth; in the hospital they feed me by the plastic funnel. Probably due to the doctor's special treatment, I recovered well physically, but I couldn't recover mentally and emotionally from those terrible days of my past. I stayed in the hospital with special permission for 2 years. I was afraid to go to the community due to my experiences of stigma because I had black reaction spots on my face and body, which looked very ugly. At the hospital, people were always murmuring about my marriage and laughed. One day I got a marriage proposal from a patient named Mr. Mohan who was undergoing treatment and heard my sad story and I married him on 5th May 2018.

I became leprosy cured by Damian Foundation India Trust and overwhelmed to have the opportunity to participate in the TLMTI's sensitization training programs with my lovely husband; indeed, TLMTI has given me a great chance to meet leprosy champions and to become a champion and also trained me vocationally for 2 years to become a professional tailor. I can never forget the help from TLM for making me a champion and APAL for giving a suitable job and employing my husband as an Administrative Officer and enable us to live happily and with dignity in mainstream society, as well as to be a role model to the leprosy community.

APAL Working States

★ Equity and Integration...



- Jharkhand
- West Bengal
- Bihar
- Telangana
- Andhra Pradesh
- Tamil Nadu
- Karnataka
- Maharashtra
- Madhya Pradesh
- Gujarat
- Chhattisga
- Odisha
- Rajasthan
- Uttar Pradesh
- Harvana
- Delhi

