

# SASAKAWA HEALTH FOUNDATION

## Monthly Progress Report

### To Executive Director of Sasakawa Health Foundation

<b>Title of the Report</b>	Monthly Progress Report
<b>Name</b>	Vagavathali Narsappa
<b>Date of Submission</b>	5 <sup>th</sup> August 2020
<b>Reporting Period</b>	July 2020

### 1. Report on activities of APAL State-Level Bodies and APAL Leaders

- Participated in the online Brainstorm Meeting
- Associated with the Government Municipal corporation distributed food grains
- Memorandums submitted to the SLOs overall India
- MCR footwear distributed associated with GRETNALTES INSTITUTIONS
- online Zoom meeting on the questionnaire to assess the impact of Covid-19 Pandemic on the lives of Leprosy affected persons
- Conducted awareness program on Precaution of COVID-19 and distributed eggs
- Recommendation letter for the Government Job
- Associated with Ward Counselor and Conducted awareness program on Precaution of COVID-19 and distributed eggs
- Masks distribution associated with SMK Jaipur
- Participated in the CORE group meeting on leprosy
- Monitoring of regular work in the Hyderabad office for Administration of corresponding mails, finance, and social media.

### Participated in the online Brainstorm Meeting

An online brainstorming meeting was held on 1<sup>st</sup> July 2020. The following members were present.

1. Dr. Takahiro Nanri – Sasakawa Health Foundation
2. Dr. Vivek Lal, Executive Director, Sasakawa India Leprosy Foundation
3. Mr. V. Narsappa, President, Association of people affected by Leprosy (APAL)
4. Mr. Venu Gopal, Vice President, APAL
5. Mr. Uday Thakar, Advisor, APAL

Mr. V. Narsappa initiated the discussion & welcomed all the participants. He briefly explained the problem faced by APAL while working with SILF for the last 10 years. He pointed out that, so many NGOs look upon affected people as a receiver and do not provide them equal partnership, dignity, and opportunity. He further added that the vision of Mr.

Sasakawa was to provide equal opportunities to affected people and to empower them to lead a dignified life. He pointed out that affected people can work in the field but they are weak in paperwork and reporting. Mr. Narsappa expects that new leadership of SILF will bridge the gap & support APAL with the equal partnership.

Mr. Venu Gopal explained, in brief, the vision of Mr. Sasakawa. He further added that, due to ignorance of past leadership of SILF, with communication and appointment of mentor lead to misunderstanding between APAL & SILF. He then highlighted that, with support and motivation from TNF & Mr. Sasakawa, the state leadership in Bihar, Odisha, and Chhattisgarh have very efficiently worked on advocacy and visit of Mr. Sasakawa to these states has become a real success.

Dr. Vivel Lal explained the 3 aspects on which SILF & APAL will work together.

1. Mutual respect.
2. Mutual trust & transparency in working
3. Strong communication.

He further added that SILF will develop a strong partnership with APAL & will involve APAL Leadership in all stages of decision. He said that leadership of Dr. Nanri will help SILF to develop a strong working partnership with APAL. Dr. Nanri explained the vision of Mr. Yohei Sasakawa to establish these two organizations to work for advocacy and livelihood projects. He shared that, APAL state leadership has a good relationship with the Government. During the Gujarat visit, Mr. Sasakawa expressed his willingness to provide Central place to APAL in decision making with SILF.

In conclusion, he said that APAL & SILF can work together at the operational level and advocacy level. He added that he & foundation is always available to SILF & APAL for any support, advice, guidance. In the end, he informed that NLEP India is going to organize one meeting on Leprosy Elimination Program during COVID-19. He requested APAL and SILF to attend the same when it is finalized.

## **Associated with the Government Municipal corporation distributed food grains**

In the date of the 3rd July, 2020 APAL Associated with the Government Municipal Corporation distributed food grains

**Introduction:** Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported by some food grains, soaps, and masks to the people affected by

leprosy those who are residing in the leprosy colonies. In most states, our APAL leaders represented and supported food aid and other key social protection services also.



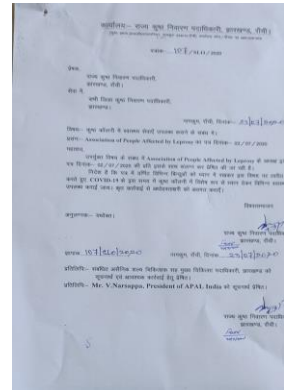
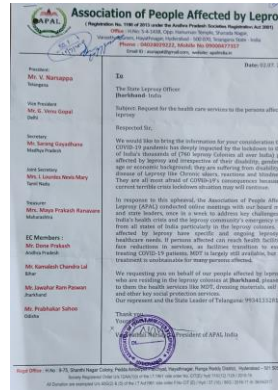
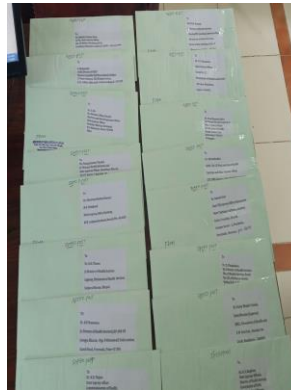
In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with the Government Municipal corporation distributed food grains to 150 families of persons affected by leprosy in Indore leprosy colony, Bhopal District, state of Madhya Pradesh. The food grains are sponsored by the Government Municipal Corporation.

The beneficiaries are conveyed their gratitude to APAL, Lepra society, and Rising Star Outreach for support food grains in the terrible COVID-19 crisis time.

### **Memorandums submitted to the SLOs overall India**

The date of the 2<sup>nd</sup> July 2020 Association of People Affected by Leprosy (APAL) submitted memorandums to all State Leprosy Officers overall India, for their consideration to provide health care services and other social protection services to the people affected by leprosy who reside in the leprosy colonies.

**Introduction:** The COVID-19 pandemic has deeply impacted by the lockdown to the lives of India's thousands of (760 leprosy Colonies all over India) persons affected by leprosy and irrespective of their disability, gender, caste, age or economic background; they are suffering from disability by the disease of Leprosy like Chronic ulcers, reactions and blindness also. Persons affected by leprosy have specific and ongoing leprosy-related healthcare needs. If persons affected can reach health facilities, they face reductions in services, as facilities transition to exclusively treating COVID-19 patients. MDT is largely still available, but reaction treatment is unobtainable for many persons affected.



(APAL) have submitted a memorandum to all State Leprosy Officers (SLO) for their consideration to provide health care services and other key social protection services to the people affected by leprosy who reside in the leprosy colonies in India. After that, APAL got a positive response from the SLO of Jharkhand; On behalf of the community affected by leprosy and APAL convey our gratitude to Respected Jharkhand's SLO for his great responsibility on us even in this terrible COVID-19 crisis.

## MCR footwear distributed associated with GRETNALTES INSTITUTIONS

On the date of the 7<sup>th</sup> July 2020 Association of People Affected by Leprosy (APAL) approached and associated with GRETNALTES INSTITUTIONS distributed MCR footwear to the people affected by leprosy.

**Introduction:** Due to loss of sensation the People Affected by Leprosy get ulcer wounds in their hands and feet. They require daily dressing of the ulcers and Micro Cellular Rubber (MCR) footwear for walking to prevent bone infections and amputation of legs and fingers.





In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with GRETNALTES INSTITUTIONS distributed MCR footwear to 100 members of persons affected by leprosy in Bunny Nagar Leprosy Association, Guggirala Mandal, Guntur District state of Andhra Pradesh. The MCR footwear sponsored by GRETNALTES INSTITUTIONS. On the occasion, the AP leprosy State Leader Mr. Nageswar Rao attended and on behalf of all beneficiaries conveyed gratitude to the sponsors for their great support to this terrible COVID-19 crisis.

## **Online Zoom meeting on the questionnaire to assess the impact of Covid-19 Pandemic on the lives of Leprosy affected persons**

In the date of 16<sup>th</sup> July 2020, Sasakawa India Leprosy Foundation conducted an online Zoom meeting on the questionnaire to assess the impact of Covid-19 Pandemic on the lives of Leprosy affected persons

### **Participants**

1. Dr. Vivek Lal
2. Prof. Nanri
3. Dr. Gopal
4. V. Narsappa
5. Venu Gopal
6. Uday Thakar

### **Discussions:**

On the meeting, Dr. Vivek Lal shared points below

I am confident that this kind of communication will positively impact our relationship and future programming.

1. Thank you for sending the revised questionnaire. I have noted that some questions have been changed. However, the length of the questionnaire essentially remains the same. I hope it is fine
2. As decided during the virtual meeting, I will now have this translated into Hindi
3. We will then do a pilot testing on a few colonies and incorporate changes if needed
4. State leaders to be trained to fill up the questionnaire
5. The data collection will be undertaken by SILF & APAL. Five colonies per state could be taken for data collection
6. IEG would be involved in data analysis, for which a TOR will be prepared
7. The data could be utilized for resource mobilization, advocacy and appropriate changes to our programming

## Conducted awareness program on Precaution of COVID-19 and distributed eggs

In the date of 22<sup>nd</sup> July, 2020 APAL conducted an awareness program on Precautions of COVID-19 in Ambedkar Leprosy Colony at Nalgonda district, Telangana

**Introduction:** In this terrible COVID-19 crisis time the health promotion information is reaching some persons affected by leprosy but others are difficult to reach due to travel restrictions and illiteracy. Persons affected have specific and ongoing leprosy-related healthcare needs. If persons affected can reach health facilities, they face reductions in services, as facilities transition to exclusively treating COVID-19 patients. People affected by leprosy who residing in leprosy colonies struggling for strengthened food because they are surviving only depending on begging, working as daily laborers, or running small shops but they lost all their livelihoods completely.



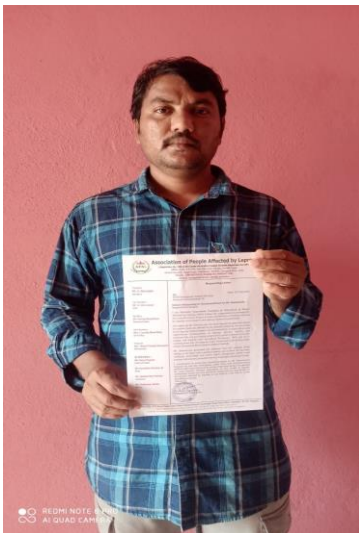
In response to this upheaval, the Association of People Affected by Leprosy (APAL) conducted an awareness program on PRECAUTION OF COVID-19 and distributed eggs to 110 families for people affected by leprosy in Ambedkar Leprosy Colony at Nalgonda district-Telangana. On the occasion, the president of APAL Mr. Narsappa Vagavathli explained about the precaution methods of COVID-19 following

1. Stay at home when you are sick
2. Avoid close contact with people who are sick
3. Wash your hands at least 20 seconds
4. Cover your cough or sneeze with a tissue
5. Don't eat raw food; thoroughly cook meat & egg
6. Avoid touching eyes, nose and mouth with unwashed hands
7. Clean & disinfect frequently touched object & surfaces
8. Avoid crowded places and traveling etc. Finally, he said that "Increase of Immunity Power ourselves is the best prevention of corona Virus". with healthy fruits and vegetables which are available.

## Recommendation letter for the Government Job

On the date of the 24<sup>th</sup> July 2020, APAL has given a recommendation letter to the child of the person affected by leprosy for the Government Job.

**Introduction:** The Government of Andhra Pradesh and Telangana sub-area released employment notifications for Ex-Servicemen Contributory Health Scheme (ECHS). In this purpose of the Job interview, Mr. Emmanuel approached APAL for a recommendation letter because the applicant Mr. Emmanuel also from leprosy background meant his parents both are affected by the disease of leprosy. He also faced much leprosy related stigma and discrimination at many places and experienced consequences of leprosy, psychosocially and economically; we are closely observed his great overcome from the stigma and studied well, completed Vocational MLT and he is working from last 10 years as a Lab Technician in Good Samaritan Cancer Hospital at Eluru district, Andhra Pradesh.



10:13 AM

**EX-SERVICEMEN CONTRIBUTORY HEALTH SCHEME (ECHS) EMPLOYMENT NOTICE**

1. ECHS Telangana and Andhra Sub Area invites applications to engage following Staff on contractual basis for ECHS Polyclinics and Regional Centres Hyderabad for a period of 11 months for Civilians and 12 months for Ex-servicemen and Widows of Ex-servicemen :-

Sl. No.	Appointments	No of vacancies	Location
(a)	CHC	03	Secunderabad-I, Vijayawada & Kakinada
(b)	Gynaecological	01	Gidder
(c)	Med Offr	07	Secunderabad-I, Gidder, RCH, Kalka, Guntur, Gokonda & Guburga.
(d)	Dental Offr	10	Secunderabad-I, Gokonda, Secunderabad-II, Guntur, Kakinada, Kurnool, Koppa, Mahabubnagar, Eluru & Nellore
(e)	Nur Asst	13	02 x Gokonda, 02 x Guntur, 02 x Secunderabad-I and 01 each for Secunderabad-I, Eluru, Kurnool, Khannam, Nellore, Mahabubnagar & Guburga.
(f)	Pharmacist	03	Secunderabad-I, Kurnool & Mahabubnagar
(g)	Lab Tech	07	Secunderabad-I, Vijayawada, Eluru, Kurnool, Khannam, Anaparthi & Mahabubnagar
(h)	Dental Hyg	09	Secunderabad-I, Gokonda, Gidder, Vijayawada, Kalka, Anaparthi, Chittoor, Kakinada & Guburga.
(i)	Physiotherapist	03	Guntur, Gidder & Chittoor
(j)	Female Attendant	09	Secunderabad-I, Gokonda, Guntur, Gidder, Kakinada, Kurnool, Khannam, Nellore & Mahabubnagar
(k)	Paon	01	Secunderabad-I
(l)	Diner	05	Secunderabad-I, Guntur, Gokonda, Vijayawada & Kurnool
(m)	Clerk	06	RCH, Chittoor, Khannam, Anaparthi, Mahabubnagar & Kakinada
(n)	DEO	04	Guntur, Gidder, Secunderabad-I & Vijayawada
(o)	IT Net Tech	02	Secunderabad-I & RCH
(p)	Chowkidar	03	Gidder, Khannam & Guburga
<b>Total Vacancies</b>			<b>86</b>

2. Interview will be held as per the details given below :-

Sl. No.	Appointment	Time	Date of Interview
(a)	CHC, Cyane and Medical Officer		21 July 2020
(b)	Dental Officer (For BDS Candidates)		22 July 2020
(c)	Dental Officer (For BDS Candidates)	Candidates	23 July 2020
(d)	Nursing Assistant and Pharmacist	present	24 July 2020
(e)	Lab Tech, Dental Hyg and Physiotherapist		25 July 2020
(f)	Female Attendant and Paon		26 July 2020
(g)	DEO, Clerk and IT Net Tech		28 July 2020
(h)	Diner & Chowkidar		29 July 2020

3. Applicants to clearly indicate all polyclinics of their choice (4) No online applications will be accepted. (5) Multi tasking & Computer

**Association of People Affected by Leprosy (APAL)**  
 (Registration No. 1106 of 2011 under the Andhra Pradesh Societies Registration Act 2001)  
 Office: 108a, 5 x 148, Opp. Laxman Temple, Sharda Nagar, Varadachari, Secunderabad-500017, Hyderabad-500017, India  
 Phone: (0822)857272, Mobile No: 9908977917  
 Email: info@apeal.org, website: apeal.org

**Requesting Letter**

Date: 23<sup>rd</sup> July 2020

To  
 ECHS Telangana Andhra Sub Area  
 Hyderabad, Secunderabad-500017

Via President  
 Mr. G. Venu Gopal  
 Deba

Subject: Requesting or recommendation for Mr. Emmanuel  
 Requested By/Author

I am Narsayya Vignarath, President of Association of People Affected by Leprosy (APAL) India, an organization working for the Socio-Economic Empowerment and Welfare of Persons affected by Leprosy who reside in the leprosy colonies over all India.

The applicant Mr. Emmanuel also from leprosy background meant his parents both are affected by the disease of leprosy. He also faced much leprosy related stigma and discrimination at many places and experienced consequences of leprosy, psychosocially and economically; we are closely observed his great overcome from the stigma and studied well, completed Vocational MLT and he is working from last 10 years as a Lab Technician in Good Samaritan Cancer Hospital at Eluru district, Andhra Pradesh.

Mr. Emmanuel possesses the ultimate "Can Do" attitude while taking on all tasks with a positive energy and a smile. He has basic computer knowledge and online works (Google sheet online work process, admission, generalization, discharges and claim work).

I volunteered to write this recommendation to Mr. Emmanuel because he has the intelligent, work ethic, and communication skills to add value wherever he works. Important thing is his growth by your concern become inspiration or role model to leprosy colonies those who are afraid for discrimination and help to the people affected by leprosy to live happily with dignity in the modern society.

Thank you  
 Yours Sincerely  
 Mr. Narsayya Vignarath  
 President  
 Association of People Affected by Leprosy (APAL)

Requester: Mr. N. V. Narsayya  
 Mangala

Joint Secretary  
 Mrs. L. Laxmi Devi  
 Tandi Bala

Treasurer  
 Mrs. Maya Prakash Rao  
 Mahabubnagar

EC Members :  
 Mr. Dinesh Prakash  
 Andhra Pradesh  
 Mr. Koushik Chandra Lal  
 Andhra Pradesh  
 Mr. Anandhar Ram Prasad  
 Andhra Pradesh  
 Mr. Prabhakar Sahas  
 Odisha

Registration: 108a, 5 x 148, Opp. Laxman Temple, Sharda Nagar, Varadachari, Secunderabad-500017, Hyderabad-500017, India  
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 Email: info@apeal.org, website: apeal.org

The APAL considered his request and provided a recommendation or requesting letter to the interviewer for their positive reflection. Indeed, this is an example of people who believe in their organization of the Association of People Affected by Leprosy (APAL).

## **Associated with Ward Counselor and Conducted awareness program on Precautions of COVID-19 and distributed eggs**

In the date of 28<sup>th</sup> July, 2020 APAL associated with 4<sup>th</sup> ward Counselor conducted an awareness program on Precautions of COVID-19 in Santhi Nagar Leprosy Colony and Santhosh Nagar Leprosy Colony at Hyderabad, Telangana

**Introduction:** In this terrible COVID-19 crisis time the health promotion information is reaching some persons affected by leprosy but others are difficult to reach due to travel restrictions and illiteracy. Persons affected have specific and ongoing leprosy-related healthcare needs. If persons affected can reach health facilities, they face reductions in services, as facilities transition to exclusively treating COVID-19 patients. People affected by leprosy who residing in leprosy colonies struggling for strengthened food because they are surviving only depending on begging, working as daily laborers, or running small shops but they lost all their livelihoods completely.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with 4<sup>th</sup> ward Counselor Respected Mrs. Vidhyavathi Vijayendra Reddy conducted an awareness program on precaution of COVID-19 and distributed eggs to 150 families of people affected by leprosy in Shanthi Nagar Leprosy Colony and 40 families in Santosh Nagar Leprosy Colony at Hyderabad.

On the occasion, the Counselor explained to the people about precaution methods of COVID-19 and said that "Say no to PANIC and say yes to PRECAUTIONS.

## **Social Protection tool (Masks) distribution associated with SMK Jaipur**

On the date of the 29<sup>th</sup> July 2020 APAL associated with Sardhak Manav Kusht Aashram (SMK) distributed social protection tools (Masks) to people affected by leprosy.



**Introduction:** Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. The Government and local NGOs are supported by some food grains, soaps, and masks to the people affected by leprosy those who are residing in the leprosy colonies.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with Sardhak Manav Kusht Aashram (SMK) Jaipur distributed social protection tools (masks) to 80 people affected by leprosy in Ram Nagar & Prem Nagar Leprosy colonies in the state of Bihar. The masks are sponsored by the Sardhak Manav Kusht Aashram (SMK) Jaipur.

The beneficiaries are conveyed their gratitude to APAL and Sardhak Manav Kusht Aashram (SMK) Jaipur for their support and help in the terrible COVID-19 crisis also.

### **Leprosy Core Group Meeting**

In the date of 29<sup>th</sup> July 2020, the Core Group Meeting on Leprosy conducted by NCPEDP

#### **Members and Participants Present:**

1. Arman Ali, Executive Director, DPI India(NCPEDP)
2. Rati Misra, Adviser, NCPEDP
3. Nikita Sarah, Head Advocacy and Communication, TLMTI
4. Dr. Vivek Lal, Executive Director, SILF
5. Dr. Dhvani Mehta, Senior Resident Fellow, VIDHI Centre for Legal Policy
6. KanchanPamnani, Advocate and Trustee, NCPEDP
7. Rama Chari, Founder, Diversity and Equal Opportunity Centre
8. Dr. P K Gopal, President, IDEA India
9. Ankit Rajiv Jindal, Founder, Friends for Inclusion
10. MriduGoel, Chairperson, Handicare
11. Tulika Das, Secretary, Sanchar
12. VagavathaliNarsappa, President, APAL

13. Uday Thakkar, Adviser, APAL
14. Venugopal, Vice President, APAL
15. Asifa Parveen, Sr Program Officer, NCPEDP
16. Meghna Sharma, Program Officer- Advocacy, NCPEDP

## **Agenda for the Meeting:**

### **Update on the Activities thus far, by Ms. Meghna Sharma, Program Officer- Advocacy, NCPEDP.**

Ms. Meghna Sharma gave a short update on NCPEDP's previous project activities and achievements so far.

She discussed the nine capacity building training organized in 9 states in partnership with APAL and NCPEDP's state partners. More than 600 people were reached out through this training. Sharing her observations from the Maharashtra training she felt that people affected by leprosy were more aware of their rights. And they were enthusiastic about approaching the judiciary for their property rights. She also discussed the letter sent by Dr. Harsh Vardhan (Hon'ble Minister, Ministry of Health and Family Welfare) to various states in August 2019 to repeal all discriminatory laws against persons affected by leprosy. NCPEDP wrote to the BJP ruled states, including the Chief Ministers, Health Ministers, Ministers of Social Justice and Empowerment, Chief Justices of the States, and even to Universities clearly defining the discriminatory laws that were being practiced in those states. Positive responses were received from some of the states/ departments

NCPEDP also filed RTIs in 19 States and Union Territories seeking information on food and consumer supplies, awareness on leprosy issues, MCR footwear or healthcare, etc. On the issue of food supplies, there was no specific data for people affected by leprosy. But there were positive responses on awareness-raising efforts. Some states have done well-using tools like nukkadnatak (Street Play) and television advertisements. The Healthcare department had a good record of the number of MCR footwear distribution but the quality of this footwear is compromised.

### **Update on EDPAL Bill by Nikita Sarah, Head Advocacy and Communication, TLMTI**

She started by appreciating the positive steps taken by the Health Minister Dr. HarshVardhan who paid attention to repealing discriminatory laws against people affected by Leprosy. TLMTI also sent letters to different states. Through a concerted effort the year 2019 saw a decline in these 119 discriminatory laws which have now been reduced to 102. She also drew attention to the unavailability of information on repealing of some laws in states as there has not been any notification.

Mentioning the EDPAL bill, she said that the Ministry of Health and Family Welfare had them asked to rework and add more flesh to the Bill and the reason being they wanted to push it to different ministries. With stakeholders consultations, the new Bill has been drafted and shared with the Ministry. And now the wait is to see how Ministry is going to respond to it.

Giving a background on the old bill she said that it had been in the pipeline since 2015 and had been sent to different ministries. Ministry of Social Justice and Empowerment had responded that since persons affected by Leprosy have already been covered in RPWD Act and therefore they had no interest in another Bill. She further added that recommendations of the CRPD Committee speak of zero discriminatory laws. There is a lot

of pressure on the Government to repeal these laws. The Ministry of Health and Family Welfare seems to be in support of this newly drafted Bill and a positive response is expected.

### **1. Update on PIL by Dr. Dhvani Mehta, Senior Resident Fellow, Vidhi Centre for Legal Policy**

Updating the Core Group on the PIL filed by Vidhi Centre for Legal Policy, Dr. Dhvani Mehta said that there has been no progress in the past one year and even now the court is just hearing urgent cases due to the pandemic restrictions. Also because hearings are now virtual there is no clarity on how the litigations would proceed.

She said she would consult with Advocate Raju Ramchandran who has been representing the leprosy issue and ask him what the best approach is. Also, advocacy has to be continued. Giving her opinion she said that demands in the petition are not necessarily things that the court gets interested in. She suggested that currently, the sector should pursue the Government to get its attention to the demand rather than keeping all hopes with the court.

Responding to Dr. Mehta's suggestion Mr. Arman Ali opined that the sector needs to keep an eye on how courts work if they start functioning in a digital mode.

Ms. Nikita Sarah also raised a query and asked Dr. Mehta if it was a good idea to continue advocacy to demand the implementation of directives given by the Supreme Court in *Pankaj Sinha v. Union of India* and *Vidhi's petition*. Dr. Mehta suggested two options: Engaging with authorities responsible for implementing these directions and also going to the court and ask for better enforcement.

Ms. Mridu Goel suggested approaching the State Disability Commissioners with demands to implement the judgment.

### **2. Introduction by Dr. Vivek Lal, Executive Director, SILF**

Dr. Vivek Lal is the present Executive Director of Sasakawa India Leprosy Foundation. He is a medical doctor and has been working on Leprosy issues for the past 10 years. In his current profile, he is looking at building synergies between the medical and the socio-economic aspect of people affected by leprosy. This was his first interaction with the group as he has recently joined this new role. He offered his support and involvement in future meetings and engagements.

### **Update on the new NCPEDP- DPI project- seeking feedback and suggestions by Ms. Asifa Parveen, Sr Program Officer, NCPEDP**

Ms. Asifa Parveen started the session introducing the new DPI-TNF project which has the following two activities proposed.

### **Capacity Building and Leadership training for Youth affected by Leprosy and Youth with Disabilities.**

#### **a. Advocacy for Policy Change on Leprosy Issue.**

The idea behind the project was to create a second line of leadership in the leprosy sector as this has been found missing. Young leadership is crucial for the sector. Thus a group of 100 youth (50 youth with Leprosy/ Family member of people affected by leprosy and 50 youth with disabilities) will be identified by the APAL and State partners and trained. These participants will be from those 9 states (Delhi, Haryana, Uttar Pradesh, Maharashtra, West Bengal, Telangana, Odisha, Jharkhand, and Andhra Pradesh) where training was conducted in the previous project and 'Chhattisgarh' would additionally be included. This was originally planned as a two days training program to be conducted during May-July but due to the pandemic situation this had to be postponed and now the training would be provided through series of Webinars on capacity building of these youth.

These youth will be called 'Champions' and will be actively involved in advocacy activities.

The second activity ' Advocacy for Policy Change' would emphasize the need for strong and continued advocacy on different pressing issues like Land Rights, Employment Opportunities, Housing, and the existing discriminatory laws. The focus will be on the 10 identified states and the Central Government.

The champions will be supported to take advocacy initiatives. There will be two review meetings with these champions to take stock of advocacy and monitor progress and also to plan future projects.

Ms. Asifa also sought feedback and suggestions from the core group on engaging these youth in advocacy and ways of making these projects more impactful.

Mr. Thakar suggested that a written communication about the project be circulated and members could respond with their suggestions by email.

Ms. Nikita appreciated the idea of the second line of leadership. She shared that a lot of organizations are working with youth. These organizations can be approached if possible to identify young people for this project. She informed that there is a Global Champions group from where young people can be identified and involved with the new project of DPI. This was a very active group and Ms. Nikita could support us to contact them.

Mr. Vagavathali Narsappa raised his concerns on behalf of people affected by leprosy. He said that just giving the training is not enough for them. There must be some interaction and monitoring with them after training programs. It was also important to ensure their financial independence. Regular support is needed for them. He suggested that the group members should come together and do something for the long term livelihood options for these youth.

**Identifying key advocacy issues - the amendment of Assessment guidelines, lobbying for EDPAL Bill, Sensitization on RPWD Act and any other issues: Key responsibilities by Ms. Rati Misra, Adviser, NCPEDP**

Ms. Misra started this session by focusing on key issues to be addressed in the next 6 months and how this group should act upon these issues. A quick discussion happened around that, starting with key advocacy issues. Key ones identified in the previous



meeting were a revision of assessment guidelines, creating awareness about the RPWD Act, and lobbying for the enactment of the EDPAL Bill.

Mr. Uday Thakar felt that the land rights of persons affected by leprosy is the major concern in many states, like Gujarat and Bihar. Taking advantage of the pandemic the colony inhabitants are being removed from the colonies they have been living in. People approached the Court in Bihar leading to a stay order being issued but that was not a permanent solution. There is an issue of encroachment as well.

Ms. Kanchan Pamnani felt that we should take up this issue as with the forthcoming elections in Bihar, this is the time to move politically. She emphasized that the group and the sector need to focus only on one state, Bihar because if it gets done in one state, it will

be easier to work in other states. She also felt that capacity building could be done anytime.

Ms. Tulika Das also suggested engaging with land rights activists who could support our advocacy.

Ms. Nikita joined in to raise concerns on the Assessment criteria. She said this is an urgent need. She said that the assessment criteria in use are completely incorrect. TLMTI and WHO worked together on the whole Assessment Criteria and this needs to be taken up by the Ministry. The current assessment guidelines do not cater to non-visible symptoms such as lack of sensation in the limbs etc and people are not given disability certificated and therefore are deprived of the many benefits due to them. There is a need to push for the correct assessment guidelines.

Ms. Rama Chari also felt that disability certification is such a crucial issue and comparatively more doable, is the group clear what should be the assessment criteria so that it can be taken up to the ministry. In her opinion, the sector can start sustained advocacy on it and get it solved. Other issues were long-drawn. Dr. Lal felt that given that evictions were currently happening in Bihar, it was imperative to take that issue up urgently.

### **Way Forward:**

1. Capacity building of the second line of leadership, land issue (focus on Bihar), and Assessment Criteria for disability certificate needs to start parallel.
2. Ms. Tulika Das will try to connect with the land rights activist to know the technicalities of such issues.
3. Starting a media campaign around evictions happening and land rights.
4. APAL will research the number of colonies in Bihar and what are the issues they are facing. This research to be completed in 15 days from 29<sup>th</sup> July 2020.
5. Dr. Dhvani Mehta to handle the legal side.
6. TLMTI, (Ms. Nikita Sarah) will take up the Assessment Guidelines issue and others can join as and when required. She will share the guidelines were prepared with the group and which has already been shared with the concerned ministry.
7. Need to organize such meetings more often.
8. Next meeting scheduled for 12<sup>th</sup> August 2020.

**b. Report on activities of the Indian Central Government and States/UTs related to leprosy control that you have learned about while conducting duties as APAL President Mr. Narsappa.**

In June 2020 there is no activity in Central/ State Government programs.

**c. Key findings which are important for SHF work**

- a. To be Concentrated Advocacy on RPWD Act and Supreme Court should be expanded to some more states.
- b. APAL to organizing more coordinated activities with other disabled sectors like DPI & NCPEDP.
- c. The regular meeting of youth leader & women empowerment programs should be budgeted and organized.
- d. To form women empowerment among colony women

**d. Difficulties/Challenges you faced during the period**

**Difficulties:** In most states, our APAL leaders represented and supported food aid and other key social protection services. The services reaching some persons affected, but many are unable to benefit from it because of structural barriers, transportation challenges, or information gaps. Persons affected are relying on the safety net of services from the Governments and NGOs, but it is unclear who is receiving what, and difficult to ensure that everyone's needs are being met

**Challenges:**

- We started office work slowly because of India Ministry of Home Affairs released new guidelines called "Unlock 1.0" that allow the opening of Private Offices, malls, restaurants and religious places in all areas except the containment zones
- We are started to conducting Awareness Program on Precautions of COVID-19 in 3 leprosy colonies
- Mostly using social media platforms and updating activities in the APAL India website

**V. Narsappa.**