

Assn. of People Affected by Leprosy- APAL

Annual Report- 2014

January 2014

APAL 1st Executive Committee Meeting:

The 1st Executive Committee meeting of Association of People Affected by Leprosy (APAL) was held on 21st January 2014 at Hotel Swagath Grand, Vanasthalipuram, Hyderabad, Andhra Pradesh.

Seven Executive members out of nine and two special invites were participated in the executive committee. As per Agenda discussed in the meeting of

- Report on constitution of organisation,
- informed current situation of Society registration,
- Bank account,
- PAN card,
- FCRA Status,
- Present financial status,
- Meeting with SILF,
- To conduct 4 workshop associated by WHO-HR,
- Involvement of His Holiness Dalai Lama- New Delhi visit.



Karnataka -National SLO's Conference

National State Leprosy Officers conference by Karnataka State Leprosy Officers with supported of WHO, ILEP, Central Leprosy Division- New Delhi on 22nd to 24th January 2014. As a special invite of Mr.V.Narsappa, President- Association of People Affected by Leprosy exposed the APAL aims & objectives and 'Issues relating to persons affected by Leprosy'.

Dr.Sumana Barua Team Leader , WHO-Global Leprosy Programme, Dr.P.V.Ranganadha Rao, WHO-Global Leprosy Programme, 23 state Leprosy Officers, Dr.Micheal Sukumar-NLEP consultant, Dr.J.Subbanna-LEPRA Society Chief Executive Incharge, Dr.Arief. Dr,Noordeen, Dr.Mani Mozhi, Human Right commissioner and others participated and had healthy discussion in during the 3 days National conference



February 2014

Anti Leprosy week :

LEPRA society and APAL organised the Leprosy walk – 2014 at Bubanshewar. College students, Nurses participated in the walk



National Consultation for Rehabilitation of People affected by Leprosy

The two-day national consultation on 18th and 19th February 2014 on 'Rehabilitation of people affected by leprosy' of stakeholders shared and discussed their thoughts, and provided an opportunity to the stakeholders to input and strategize into the recommendations to be developed by the Ministry of Social Justice and Empowerment at Silver Oak, India Habitat centre, Delhi.

The conference with Rehabilitation service and early identification for Medical intervention, Therapeutic Interventions and Aids Appliances, Educational Rehabilitation (Primary/Secondary/Higher/Vocational), Social and Psychological, Economic Empowerment, Rights and entitlements and Sharing of best practices and experiences from the field

Mr.Narsappa has presented on Social Stigma & Psychology and explained the required opportunity, Disability categories, Special guidelines for people affected by Leprosy, social stigma and Psychology

Bihar –Pension

Mr.Badrinathkumar Rane -Block Development Officer – Raxaul issued disability certificates and pension @ Rs 1500/- to 136 patients for 2 months Rs.3000/- on 21st February 2014 to the biggest colony of Raxaul - Bihar state.

There are 150 leprosy affected persons in the colony and Mr Rambarai Sah- Executive member of APAL with all his hard efforts the pension enhanced from Rs 200/- to Rs.1,500/- sanctioned by Bihar state Government



Gandhi Smriti and Darshan Smurthi

The Gandhi Smriti & Darshan, Rajghat in is organised Seva Yagya, an initiative to promote the Gandhian volunteer spirit for people with leprosy and showcase their talents and potential. The Seva Yagya will be organized to observe the Kasturba Nirvan Diwas on February 22, 2014.



The objective of the Yagya is to highlight the work and efforts of people affected by leprosy and those who are cured.

A dialogue will be organized where the people with leprosy will discuss their problems and concerns with other concerned people. The thrust will be to develop understanding on issues of inclusion and mainstreaming the persons with leprosy.

His Holiness Dalai Lama New Delhi Visit:

Tibetan Spiritual leader His Holiness Dalai Lama visited Tahirpur Leprosy colony of Kasturba Gram Kusht Ashram complex on 20th March 2014. The event organised by Association of People affected by Leprosy and Sasakawa India Leprosy Foundation.



Padmasri Dr.P K Gopal- President IDEA India, Mr.V.Narsappa, President, Mr.Venugopal Vice President, Executive members and Advisor Mr.Udya Thakar from Association of people Affected by Leprosy and Dr.Vineetha Shankar Director of SILF and her staff and other local colony people participated in the meeting.

His Holiness Dalai Lama visited the Tahirpur Leprosy colony interacted with colony people of Jhali Devi 55 year old stayed 40 years in the colony and shared her problem to His Holiness Dalai Lama; as still we make living by begging. The Spiritual leader His holiness Dalai Lama expressed his willingness to



help leprosy patients over the next five years using the royalty his Trust receives from the sale of books written by him and also people spend money in luxuries way are foolish. They should spend money on people who are needy and poor. All colony peoples are delighted his speech. Mr Uday Thakar translates His Holiness speech from English to Hindi.

Welcome addressed by Dr.Vineetha Shanker Executive Director of SILF and presides over function. Bouquet presented by Ms.Maya Ranevare and colony other person to His Holiness. Mr.Yohei Sasakawa, Chairman of The Nippon foundation and WHO Goodwill Ambassador for elimination of Leprosy addressed to colony people shared his experience in the Leprosy services.

LEPCON 2014

29th Biennial Conference of Indian Association of Leprologists (IAL) –“LEPCON 2014” On March 28-30, 2014, was organized at PGIMER, Chandigarh.

Behalf of APAL Mr.Venugopal, Vice President attended the presented the presentation on “Remaining challenges of People affected by Leprosy”.

He has explained the importance of Medical Rehabilitation, Human Rights and Advocacy, Social stigma & Discrimination.

DPMR Programme (Disability Prevention and Medical Rehabilitation):

- POID Camps at PHC Level (To organize),
- Ulcer management (No Sufficient ulcer materials),
- Provision of MCR Foot wear (No periodically, No Proper size),
- Reaction treatment (No TH Wards) & Provision of disability certificate (issuing Under Orthopaedic Guidelines)

Re-construction Surgery: Special Training for All surgeons on RCS, Trained Physiotherapy on Leprosy, Operation to be done in general OT

CME Theme: “Sustaining Leprosy Elimination” Plenary Lectures, Workshop, PG Quiz, NLEP Session, Plenary Lectures, Award papers, Free papers/Posters

Key Note/ Plenary Speakers

Dr V M Katoch - DGICMR, SDHR, New Delhi

Dr Jagdish Prasad - DGHS, MoHFW, New Delhi

Dr C M Agarwal - DDG Leprosy CLD, MoHFW, New Delhi

Dr Sumana Barua - GLP, WHO

Dr Diana Lockwood - LSHTM, London, UK

Dr Paul Saunderson - Editor, Leprosy Review. American Leprosy Missions, USA

Dr Richard W Truman - NHDP, USA

Dr Steve Walker - LSHTM, London, UK

Dr. Ann Aerts - NOVARTIS Foundation for Sustainable Development, Switzerland are actively participated in the conference.

April 2014

NCRPD Meeting

The National Committee on the Rights of Persons with Disabilities (NCRPD) invited the Association of People Affected by Leprosy for this meeting on 12th & 13th April 2014 at USI Residency Resorts, Rao Tula Ram Marg, Vasant Vihar, New Delhi. In fact, the idea of a new law on disability came from a meeting of NCRPD.

Inauguration session was started. Welcome address by Mr.Javed Abidi Director. And the participation they have introduced themselves and he



has explained the main purpose of the meeting and also he shared his experience the disability legislations is the way forwarded. Mrs.Nita Panchal and Gayatri Kaul (Handicap International Project) have given their speech on Good Practice on employment and accessibility.



Mr.V.Narsappa, President of APAL mentioned that there are separate special guidelines to assess the disabilities like in visually disabled, Hearing impaired, orthopedically handicapped. The leprosy disabled persons are assessed under orthopaedic disability guidelines. There is a need to develop special guidelines exclusively for assessment of leprosy disabilities (including Loss of Sensation). Finally he has suggested that we are all equal categories and work together in one platform.

Report on Odisha State NLEP meeting:

Odisha state conducted NLEP review meeting on 16th April 2014 at LEPRO office, Bhubaneswar, Odisha. In the meeting Public health Director, Joint Director -cum-SLO, Deputy Director Leprosy, Regional Director,-LEPRO, HKNS Secretary, Dr. S.N. Pati- NLEP Consultant, Mr. Umesh Chandra Nayak-APAL State leader, Mr. Eswar Rao-PT LEPRO All District Leprosy officers are participated.

During the meeting the follow points are discussed.

1. Mr.Sasakawa Visit
2. NLEP Programme in Odisha
3. New NGO's scheme and etc..

1. Mr.Yohei Saskawa Odisha Visit: All the members and participants are suggested that Good will ambassador Mr.Sasakawa will be visit in September or November 2014. It suitable for him and also have to do some ground level work. Before his visit to write a letter all department related pension, civil, human rights
2. NLEP Programmes In Odisha: All District Leprosy officers submitted presented their activities of respective districts. Action plan of 2014-15 are discussed in the meeting.
3. Placed in the NLEP proposal to NGO scheme-4 the districts Bargarh, Balangir, sonapur, Jharsuguda, Sundergarh etc. But it did not place to NGO scheme-5 (Awareness). NLEP coordination committee (Joined director leprosy, and to other) said that not give to Association of People Affected by Leprosy (National forum) till now. Reconsideration for it, we can write letter to DDG India. Applied for 24 NGO schemes. Among those, only NGO scheme-4 is placed in NLEP proposal.

Right to health of persons with disabilities'

HRLN in partnership with the Indian Association of Muscular Dystrophy (IAMD) and the National Alliance on Access to Justice for persons living with Mental illness (NAAJMI) is organising a two days National consultation on 'right to health of persons with disabilities' on the 19th and 20th of April, 2014. The two days consultation held at the Vishwa Yuva Kendra, Chanakya puri, New Delhi.

Welcome address by Mr.Rajiv Raturi of Director HRLN and introduction to consultation of meeting. Jayna Kothari, Centre for law and policy Bangalore has explained the background situation of Right to Health to PWD act.

Deepika Nair and Saathi, Delhi are spoken on International and domestic law in right to health.

The topic of Disability and Nation Urban Health Mission by Mr.G.Praveen, VSO Delhi conveyed the rights. Dr.Satendra Singh, UCMS, Delhi has delivered his speech on Health rights of PWDs and accessibility.

Advocate Roma Bhagat spoken on health concerns of persons with hearing impairments. Dr.Ratna Devi -Health (Alliance of patients) Delhi speaks on creating a National for Voice, Health care and Access.



May 2014

POID Evaluation Disseminations

Prevention of deformity and prevention of worsening deformity is most important aspect in NLEP. Hence FAIRNMED in co-ordination with RISDT in East Godavari & GRETNALTES in Guntur districts implemented POID project.

The POID Evaluation Dissemination programme conducted at Directorate, Sultan Bazar, Koti, Hyderabad on 21st May 2014. Dr.J.Ravi Prasad welcomed all dignities who attended the POID Evaluation dissemination report.

Dr.B.Raja Rao, Medical Superintendent of RISDT has explained the goal of POID project and importance of activities of POID camps at village level with collaboration of PHC staff. During the camp Nerve Function Assessment for newly diagnosed cases. POID camps of 1090 at Guntur district and 1056 camps in EG districts, During the presentation MCR footwear 6066 in Guntur and 7506 in EG districts and self-care kits provided in Guntur districts 7881 and 10990 kits in EG districts.



Mr.John Kurian George Director of Swiss Emmaus, Chennai has explained the POID end evaluation dissemination report. Dr.Tarachand Naidu, State Leprosy Officer, Andhra Pradesh has given very nice feedback of POID camp. Dr.Uma Devi, ADMHO Guntur & Dr Pavan Kumar ADMHO East Godavari shared their experience.

Delhi SLO NLEP Review Meeting:

Delhi State Leprosy Officer conducted review meeting on 23rd May 2014 at Directorate of Delhi Health Services

A meeting was conducted by the SLO of Delhi State at the directorate of Delhi Health Services to review the present activities and to prepare action plan-2014-15. During the meeting Delhi SLO review the DLOs achievements their respective areas.

All DLOs and other staff attended and read out their reports. The SLO asked the DLOs to speed up their activities for good results in detection of new cases, treatment, RCS etc. Mr.Venugopal also explained about our organization and our expectations from DLOs and leprosy control unit of Delh.i

APSLO NLEP Review meeting:

Andhra Pradesh state Leprosy Officer conducted review meeting at central Hotel, Lakdikapool, Hyderabad on 23rd May 2014. All district Leprosy Officers (ADM&HOs), Dr.J.Subbanna-Deputy CEO LEPR, Dr.Micheal Sukumar – LEPR, Mr.V.Narsappa-APAL, Mr.Sathyanrayana - SLAP, Dr.Ananth Reddy- Sivanada Rehabilitation Home Kukatpally, Dr.Krishana



Murthy Medical Officer DLRC and other NLEP staff attended the meeting.

Dr.Tarachand Naidu has explained the achievements of Andhra Pradesh activities and last meeting of the Andhra Pradesh meeting. Shortly the Andhra Pradesh state will be separated 2 regions as Telangana & Seemandra. All ADM&HOs presented their district achievements by presentation and Mr.V.Narsappa has presented APAL activities and Human Rights.

Dr.Tarachand Naidu to be retired by this month, Hence all ADM&HOs gave farewell party to SLO AP Dr.Tarachand Naidu. This is last meeting of Andhra Pradesh SLO review meeting.

HKNS Review Meeting:

HKNS contacted consultation meeting with Leprosy Affected Persons and member of leprosy Institution on 24th May 2014 at Auditorium, Durgabai Deshmukh Hospital and Research Centre, Vidyanagar, Hyderabad.



Additional Director of leprosy Dr. Tarachand Naidu and NLEP staff, Mr.Narsappa-President of Association of People Affected by Leprosy Mr.Ashim Chowla- CEO LEPRASOCIETY, Dr.J.Subbanna-Deputy CEO LEPRASOCIETY, Mr.Janardhan Reddy- HKNS members, HLC & HS staff, Dr.Ananth Reddy Team- Shivanadna Rehabilitation Home Kukatpally, Mr.Kumar vel-Word & Deed and DLO- Ranga Reddy dist. NLEP staff& Mr.Sathynarayana-President of SLAP participated in the meeting.



The purpose of the meeting is to discuss the identified issues and possible solution for leprosy in terms of case detection, diagnosis, treatment and rehabilitation.

Mr.Janardhan Reddy welcome the all the participants and expressed the HKNS activities. AP SLO Dr.Tarachand Naidu spoken in this occasion the situation of Andhra Pradesh, especially he has mentioned the importance of case early detection before disability.

NLEP - Review meeting for SLO's of High endemic States:

NLEP - Review meeting for SLO's of High endemic States conducted at Pune on 28th & 29th May 2014, on 'Programme Progress of APAL'. Dr.C.M.Agarwal-DDGL, Dr.S.P.Sood, Dr.Vivek Lal, Dr.R.N.Sabat, Dr.Arif, Dr.Milnd Chavan, Dr.J.B.Singh, Dr.M.L.Gokak, All state Leprosy Officers, Mr.Bhimarao Madhale, Treasurer-APAL attended the review meeting.

All State Leprosy officers presented the presentation on his state performances of Action taken on recommendation of last SLO conference held at Bangalore in January 2014, Physical & financial Progress, Action plan 2014-15, and Proposed interventions during the year 2014-15.

Mr.Bhimarao Madhale has explained the DPMR activities at PHC level and MCR footwear to get very difficult in personal



basis measurement and periodically, delay NLEP staff appointment, TH Wards are not functioning, Ulcer material not issued in some states. Patients are not getting general treatment in govt. Hospitals especially disability patients. He had concluded in early case detection before disability.

Dr.C.M.Agarwal has explained the Programme status on 31st March 2014 and Action Plan 2014-15. WHO country office has given support to NLEP during the 2014-15.

June 2014

IPH Meeting: A Meeting with Institute of Physical Handicapped (IPH) under (Ministry of Social Justice & Empowerment, Govt. of India) on 8th June 2014 at IPH office.

Mr.Venugopal-Vice president of APAL had meeting with Mr.R.K.Sharma, Asst. Professor/Administrative Officer, TLM representative also participated in the meeting. He has furnishing below the details of meeting.

The director of IPH had a meeting 3 days back with the Secretary of Social Justice Ministry and had discussions to add the needs of physically handicapped people in the 100 days' work plan of the Ministry. Mr.Venugopal has explained him about our organization and asked him to invite us to know the ground facts and living standards. He accepted and promised to invite us in further meetings.

He saw the minutes which is mostly based for appliances and some awareness program. They added about the colony people is mainly land allocation and sanitation only. I suggested the following points about which Sharma agreed and assured to have after having discussions with the Director.

Leprosy Post –Exposure Prophylaxis:

Leprosy Post –Exposure Prophylaxis inception workshop held at ELMI Hotel, Surabaya, Indonesia organised by Netherland Leprosy Relief from 10th to 12th June 2014.

Inaugurated of the workshop by Prof.Dr.Agus - Director General, Directorate for CDC&E, Ministry of Health, Indonesia, Dr.Khanchit- WHO representative, Head Provincial health Office East Java, Dr.Ann Aerts – Head Novartis Foundation, Swatzerland, Mr.Jan van Berkel Director of NLR- Netherland and Dr.Wim Van Brakel has explained the important of workshop for new approach for leprosy control Programme.



Dr.Wim Van Brakel, Senior Technical Consultant, NLR, Netherland has given warm welcomed all the participants and given introduction and purpose of the Leprosy Post-Exposure Prophylaxis project. Evidence of Post–exposure Prophylaxis (PEP) for leprosy and of approaches used to date. He has explained on Contact tracing and PEP approaches and operational aspects and also perception of leprosy studies.



Mr.Narsappa-President of Association of People Affected by Leprosy raised some question of

1. Without skin smear how can diagnose the cases and classified the types and RFT ?
2. During the treatment patient suffering from Reaction, who is the response to take care?
3. Prophylaxis treatment given to family members, surrounding neighbours and office staff will acceptable?
4. The patient how long to take Prophylaxis treatment.

SERP-CEO:

Mr.Narsappa-President APAL, Mr.G.Sathynaryana- Andhra Pradesh State Leader of APAL and President SLAP met Mr.Rajashekar- IAS, SERP (Society for Elimination of Rural Poverty) on 18th June 2014, regarding pending pensions for leprosy affected persons due to bio-metric.

Mr.Narsappa and Mr.G.Sathyanaryana has explained the situation of colonies people without thumb impression to get pension.

Mr.Rajashekar IAS promised to sanction pension for leprosy affected persons without bio-metric. Mr.Ramesh-Secretary and Mr.Subba Rao-Treasurer of SLAP also went to SERP office.



Bihar State-Pension:

Bihar State leader Mr.Kamalesh and Executive member Mr.Rambaraiah had discussion with Bihar Government to get pension for our people living in the colonies on 24th June 2014. They both are happy to inform that recently our affected persons of Bihar state have started getting newly made leprosy Pension.

After elections Leprosy Affected Persons of Gaya, Patna, Sitamarhi, East Champaran, Nalanda have received their pension and felt them very happy and satisfied.

In other districts the matter is in process and we are involved in it seriously.

July 2014

Meeting with DDIPH:

Mr.Venugopal Vice President-APAL went to Pandit Deen Dayal Upadhyaya Institute for the Physically Handicapped (P.D.U.I.P.H) is an autonomous organisation under the administrative and financial control of Ministry of Social Justice and Empowerment, Govt. of India on 10th July 2014 at his premises to discuss with Mr.Rajnish Sharma, Asst. Professor regarding Colony's needs.

Mr.Venugopal met Mr.Rajnish Sharma handed over the Delhi High Court order which he wants to produce as an example to Central Welfare Ministry to make land allocations to the colonies all over India. He has explained the situation of colonies in India, nobody have ownership of land and basic needs of amends of road, Sanatorium of Toilets, Electricity, Drinking water etc.

LEPRA Society Silver Jubilee :

LEPRA Society celebrating Silver Jubilee celebrations at New Delhi on 11th July 2014 at India Habitat Centre. Behalf of Association of People Affected by Leprosy- APAL, Mr.Venugopal –Vice President participated the meeting.

Mr. Alok Mukhopadhyay CEO Voluntary Health Association of India, Dr. VM Katoch - Director General ICMR, Mr. Phillip Lloyd, Ms. Meena Gupta -Chairman LEPRA Society participated in the celebration



Mr. Ashim Chowla –Chief Executive Officer LEPRA Society welcoming Mr. Alok Mukhopadhyay, Dr. Subbanna welcoming Dr. Katoch, Dr. Sonia welcoming Ms. Meena Gupta and Mr. Robin welcomed Mr.Phillip for dais. Lighting of the lamp by the guests of Mr. Alok Mukhopadhyay, Dr. VM Katoch, Mr. Phillip Lloyd, Ms. Meena Gupta, Mr.Ashim Chowla and Dr.Subbanna Jonnalagada

It is totally focused on their services and the present conditions of leprosy in India and need of services.

Odisha NLEP Review meeting:

Odisha State NLEP review meeting contacted at LEPRA Regional office, Bhubaneswar on 11th July 2014. Joint Director, Deputy Director, Administrator officer, Dr. S.N. Pati, Consultant, Mr. Umesh Chandra Nayak, State-leader, APAL, Honorary, Secretary, HKNS, State Branch, Director, RLTRI, Aska are participated in the review meeting.

Discussion Point:

- Discussion on proposed Project Implementation Plan 2014-15.
 - Discussion on proposed Odisha Health System Program support for the year 2014-15.
 - Training plan for the year 2014-15.
 - Finalization of monthly activity report of DLCs.
 - Finalization of operational areas of Physio-technicians.
1. Project Implementation Plan 2014-15
 - a. Odisha Govt has given 5.86 crore rupees for PIP. 184 posts for paramedical-worker were granted by central govt to Odisha in last year. But still it is not cleared in budget. It is insured. No any budget system for Dresser in every colony.
 - b. Only two districts (Mayurbhanj and Sundergarh) proposals have been send for two NGO scheme-4. A proposal for sanction money to two NGO scheme through Odisha has been sent. But we applied 24 NGO scheme-4.
 - c. State leader Umesh Chandra Nayak, objected that in Odisha there are 94 colony. But every colony cannot get sufficient dresser or bandage, gauge or MCR footwear. He said

that it should be appointed dressers and provided bandages, gauge and MCR footwear I to every colony.

d. State leader objected that it should be given 30 NGO scheme-4 (disabled care).

e. It should be increased 200 rupees for each survey of ASHA etc.

2. Training plan for the year 2014-15. Training programme give to doctor and ASHAs.

His Holiness & Sasakawa Education fund:

Discussion on the proposal of His Holiness & Sasakawa Education Scholarship Fund at SILF Office on 18th July 2014. Mr. Masato Seko, TNF, Dr. P.K. Gopal, IDEA INDIA, Dr. Vineeta Shanker, S-ILF, Mr. V. Narsappa, Chairman, APAL and Mr. Venugopal, Vice – President, APAL.

His Holiness Dalai Lama made a tentative commitment to provide a similar account for four additional years, subject to availability of funds from the royalty of his book. TNF proposed that this fund be used for the education of students from leprosy colonies and requested S-ILF to be the implementing agency for the scholarship.

The details of the scholarships would be worked out between TNF, APAL and S-ILF for which the present meeting was held.

Name of the Scholarship: It was decided that the name of the scholarship will be His Holiness the Dalai Lama Sasakawa Education Scholarship. Leprosy affected / cured children and first generation students from leprosy affected families residing in the colonies will be eligible for the scholarship. The scholarship will be available to Class XII and Class X students.

It was decided that this funding would be available for only

- i) Graduate courses
- ii) Graduate courses which would lead to employment. Hence, ordinary Bachelor of Arts (B.A.) and Bachelor of Science (B.Sc.) were not to be covered under the scholarship.
- iii) Course duration could be anywhere between two years to three years.
- iv) Scholarship would be available for study in colleges and institutes of repute
- v) Students would be responsible for admission on their own.
- vi) Selection would be on the basis of merit

NLR Meeting :

Mr. Venugopal VP –APAL attended the meeting with Dr. Arif and Dr. Miglani at NLR office and the discussions on 25th July 2014.

Dr. Arif asked his employ to explain about the activities taken up by NLR with the involvement of State Leaders. Mr. Venugopal admitted that may be but our central committee is unaware of the activities due to lack of any information to central board. You people are directly approaching the state leaders but not sending any information at least at the initial stage of taking up activities to our APAL leaders. He admitted the communication gap from both sides which should be solved.

Afterwards discussions took place on future plans. A concept of joint activities explained by Dr Arif in 6 states they are working. A meeting of 4 persons from 6 states leaders, board members, state welfare officers and NLR shall be arranged.

A road map of the needs of states shall be chalked out together. Working areas of NLR and APAL shall be marked. Work plan shall be drawn. NLR shall work to avail funds for the meeting. Further rising of funds for activities shall be discussed.

We have the plans in our budget and capable to work in all spheres and will be happy by the involvement of NLR. Mr.Venugopal thanked to call me for discussions. The rest I will let you know personally and wants your immediate suggestions for further action if necessary.

August 2014

WHO –SEARO Meeting –New Delhi:

Mr. Narsappa, Mr.Venugopal and 2 local members of Delhi M. Kadir and Mrs. Babli were attended the informal meeting with WHO SEARO at New Delhi on 1st August 2014. Dr Panikar, Dr Barua and Dr. Ranganadha Rao were attended on behalf of WHO.

The subject was including of people affected in planning and implementing leprosy services in Global Leprosy Strategy 2016-20 & in 5 year plan of Govt of India and to hear the views and suggestions of representatives of affected people.

The views and suggestions of us are:



- Practically the work is not going on as shown on papers by NGOs or ILEP agencies. Involvement of people affected in programs at the initiative stage is only to fulfil the guidelines and still we are sitting in back bench.
- We are not treating as partners but as a receiving end by all. APAL is our representative organization and working with strong network. We are capable to plan, implement and monitor any activity. Whatever program implemented by any agency our state leaders are working at the bottom level without any identification of them or APAL. Why programs should not take up directly with APAL by providing funds and ask the agencies to involve with us? It was decided two years back to translate the guide lines printed in English in to local languages to make it useful. Why doesn't the responsibility give to APAL by providing funds? Clearly we want to be in centre of all programs and the NGOs should support us. By the support of Mr Sasakawa and guidance of Dr P K Gopal now we are on a single platform and capable to achieve our goal.
- Medical issues also discussed about treatment, early detection, providing of dressing materials, RCS and MCR footwear. We have expressed not satisfaction with present services and suggested to involve us at every stage. To be organize workshop for all states leader to know the ground facts and suggestions for proper strategy.

APAL Informal Meeting:

APAL informal meeting held on 13th August 2014, at Hotel Swagath before Executive meeting and plan for activities to be covered in coming months. Mr.Narsappa-President, Mr.Venugopal Vice President Dr.P.K.Gopal – Senior Consultant and Mr. Uday Thakar – advisor participated and planned the meeting/training schedules

NLEP Meeting:

NLEP quarterly review meeting held on 19th August 2014 at National Head Quarter of HKNS conference hall, Red Cross Bhawan, New Delhi.

Behalf of APAL Mr.Venugopal has participated the NLEP quarterly review meeting.

The SLO Dr. Bhagotia, all DLOs and medical staff of Delhi Leprosy Cell attended the NLEP review meeting. Dr.P.V.Ranganadha Rao and Mrs. Rasmi Shukla from World Health Organisation (WHO) were present in the meeting. All the DLOs presented their work reports. Mr.Venugopal has suggested to involve leprosy affected persons in NLEP were asked by Dr. Bhagotia and my suggestions were as fallows;

1. Affected persons can help to boost up the work of cases early detection and treatment completion. So identify capable persons as volunteers and Pay incentives.
2. Providing of cobbler training to Affected Persons and to provide material and instruments.
3. Appointment of affected persons as dresser of ulcer wounds.
4. Identifying of capable persons to involve in advocacy, counselling and awareness programs.
5. Providing of support under NGO schemes.
6. Forming of committees from State Level to district level by involving affected people.
7. Participation in planning, implementation and coordination of programs.
8. Implementation of Bangkok adoptions 2013.