

Amici News

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Love is sharing others feelings:

Raoul Follereau



AIFO

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Seasons greetings to you all, as we come to the end of the year. During the last three months various important activities had taken place. The National Programme Managers from SEARO countries with WHO delegates from GLP / SEARO, and ILEP members participated in this important meeting in Dhaka, Bangladesh. Dr. Jose from AIFO had participated in the meeting. One major issue that came up in the meeting was to rethink and focus on Case Detection Methods – through active search, since relying on IEC activities alone did not suffice adequate early detection of Leprosy case and that complacency had evaded in the National Leprosy Eradication Programmes. There were also recommendations to carry out active case detection appropriate to each region. A more detailed official communication from WHO will be released in due course of time.

It is been realised and recognised by AIFO – India and our partners that expertise in leprosy is diminishing, and increased demand for referral services for patients with complications. It would be worthwhile to assess the needs and initiate training programmes to ensure expertise is sustained.

Placing on record the appreciation of Catholic Hospital – Borgang, Assam for their initiatives to provide quality Leprosy Services and in carrying out Reconstructive Surgeries for patients from surrounding districts. Without the support of The Leprosy Mission and LEpra, it would have been a difficult task for which each and everyone will remain thankful and special thanks for Dr. Jerry Joshua. We are thankful to Dr. Helen Roberts who had all the time being very supportive and helpful in providing technical support from their departments of Footwear and Occupational Therapy and Kameswara Rao from LEpra, whose expertise was utilized for the patients who underwent Reconstructive Surgeries.

Dr. Rajan Babu often and occasionally joins us in supporting, preparing proposals along with AIFO Coordinators in providing his consultancy. Dr. Rajan Babu is well know for his commitment and passion towards leprosy, his long tenure in the field of leprosy devoting his time in training, monitoring, supervising evaluating programmes at local, National and International levels

During the last three months there were important crucial decisions making workshops and meetings held in collaboration with WHO, Central Leprosy Division State NLEP and ILEP members, and one such important workshop – Role of NGO's was held in Hyderabad.

The First CBR World Congress held in Agra and Pre and post Congress workshops were conducted by AIFO, participants from our partners expressed that they benefited a lot, sharing experiences interacting with participants from all over the world was a learning experience.

We appreciate Jayashree for her willingness to support affected persons and look forward.

About my tryst with Leprosy



Dr.Manimozhi, Mrs.Lucy, Mrs.Jayashree

The year was 1983. I was 21 years old. I had enrolled for the Chartered accountancy course, after having completed my graduation in science. For about a few months I had begun to experience a peculiar 'tug' on the little finger of my right hand. I also noticed a huge glistening pinkish patch on my right arm, around my elbows. My parents took

me to meet a skin specialist, who took a biopsy of my skin. Even before the results of the biopsy was out, some intuition, premonition of a doom egged me to look up a few medical books in the central library of the city I lived in, Coimbatore. Even before my family broke the news to me, I had realized that I had contracted Leprosy.

From being a confident, young woman who had the whole world under her feet, I felt seeing my world slip away from under my feet on that moment of realization. From being someone who wanted to speak up, say things how they are, I turned into someone who from then onwards will have no voice. I became voiceless, opinion-less and future-less. My family was devastated too – however they handled the problem in hand in the most compassionate way that was possible. My sister Shri, older to me by two years, took charge of my emotional, physical and psychological life by being around me constantly, playing tricks like knocking on the bathroom door pretending she wanted to use it, if she found me taking longer than she thought to be normal, eating out of my plate – everything to ensure that I got it that they, my family were ok about what happened to me, that I was not going to be abandoned, and that they were not going to allow me to take my own life should such thoughts cross my mind.

I was a gift of God – the year 1983 was also declared to be the year when the Multi Drug Therapy (MDT) was introduced in our city. Dapsone which I was prescribed by the doctor, was proving to be ineffective. My right hand began to develop the claw. The patch grew bigger. Again Shri took charge, and my parents were persuaded to change my doctor. Dr Rajan let me understand that the MDT would cure me. Before that I

also underwent an operation to move my ulnar nerve to release the clawing effect which did not do much to my situation. However, I was on the pathway to recovery. We did not speak about my situation at home. There was always a silence around all of us. I remained silent as I felt I had lost the right to speak. I felt guilty that I was subjecting my parents to so much of torture. Precisely to ease their pain, I really wanted to cure myself. Soon I was a wreck – the fear, anxiety, the worry for my lack-lustre future was so big, I began to have indigestion, sluggish liver, multiple pre-mature ventricular beat, puffy eyes, and every other symptom of a sickly person, that soon I was swallowing Indral, Valium and a few other medicines in addition to the MDT treatment I was on.

By 1987 I had moved to Bangalore. I wanted to move to a new city and I convinced my parents to let me go. Here I had the advantage of anonymity. No one walked up on the road and asked me, ‘Jayashree, what happened to you? Why have you lost weight/ looking charred/ looking sick/..’ etc etc which was the way I began to be greeted in my home city. I also could avoid looking at the saddened eyes of my parents, avoid seeing in their eyes what I had become – someone unlucky, and doomed. In Bangalore I was on my own. Meaning, I had to fend for myself including medically. I would buy my own dose of medication

whenever I felt there was some 'germ attack' - my own discovery that I believed was true - the smallest tug in my little finger to me meant I was being attacked by germs and I needed a lot more of medication. Of course, my biggest challenge used to be to find a quiet time in the neighborhood medical store - I would write out the names of the tablets, hang around the store till the crowd emptied, and with heart beating very loud, I would push the paper to the chemist, barely making eye contact with him. Those days my biggest fear was the fear of being discovered by my then best friend Chita - I would hold her little babies in my arms, and feel like an imposter. I was sure that if Chita were to come to know that I am being treated for leprosy, she might scream at me, and ask me to drop her babies to the floor and leave her house, never to return. I had to keep the secret of what I 'really' was, close to my chest - it was suffocating to say the least. I felt like an imposter all through while interacting with people. I took up a trainee position in a CA firm and hid my condition from all. I felt older (although I must have just been a few years senior to most students), I felt like a liar, like a kind of an outsider who did not belong. I made do with pen-friends, except for Chitra, and lived in a make-believe world where my only hope would be when I find another handicapped man with whom I could build a family.

By 1989 I had found happiness

in Bangalore - I met Dr. Paul Neelamkavil, who helped me in removing my fear when he told me that I had not only cured myself, but also my whole neighborhood. His words worked wonders for me. He even gave me a letter introducing me to Sister Mary *Mascarenas* who was involved in the work of leprosy rehabilitation in Sumanahalli, Bangalore, on my request that I would like to work for this cause. Of course, I never did meet Sr. Mary. It was too much for me to meet her. I did not know how I could work for leprosy. But every time I saw a beggar on the road, begging with his stubby hand asking for alms, I dropped a coin into his hand, and silently apologized to him, saying, 'Sorry, brother, I have let you down. I am like you only, I am just privileged that my family did not kick me out of my home, whereas yours did. I am truly sorry.' I truly felt that I belonged with them. I lived for a long time, being grateful to my family for not asking me to leave the house. I was an outsider, within my home. And this, notwithstanding the love and support of my family, especially my sisters - Shri, the older one and Sangu, who is younger to me, and my parents.

That year I also met a young happy man - he was studying for CA too. I marveled at how happy he was. I had not remembered what it was to be happy for a long time. Maybe I did laugh. But happy? I wondered what that was. This young man asked me

out, and when I blurted to him that I am a leprosy cured person, he held my hand, and told me that's not wrong and I felt as if the birds were singing, that the butterflies were flying again and that all was well with the world. I married him, feeling grateful, and always relating to life from a place of wonderment. I did not belong anywhere. But I wanted to have a family with this man, and sadly kept trying to be happy. In the meantime tragedy had struck us, my sister Shri died in a road accident in 1993, leaving behind her husband and a 4 year old lovely baby girl. My sister's death struck some common sense into my head – I began to see life for what it was. I had made a big deal of my disease – but here was a bigger problem – everyone in my family had to deal with the death of someone so young, so beautiful and so full of life. I began to strike back at life – first at God, blaming him for the games he played, and then began to assert myself. I began to seek happiness for my own self. My husband left me in 1995 and I became free and happy for once. In 1997 I declared myself free, and happy and began to immerse myself in volunteering work. Nothing gave me more joy than being a leader in an organisation that helped people discover themselves. Till 2011 I was with this company, making a mess of myself financially, but being truly happy when being with people. In the meantime, my sister, brother were married, settled

in their family life, and my little niece grew up to be a young confident working girl. I too began to look for living my family life again. I re-married, after a long gap of living the life of a single woman, in 2010. My husband Jayant Gandhi and I now run a successful business in coaching of senior executives in Multinational companies, and we are happy with what we do. He too has a marriage that did not work – when I met him, it was easy for me to give him the strength to deal with his situation.

The fact that I got reconciled to being 'deserving' of money, wealth, and the worldly possessions, and being emotionally in a relationship of caring and sharing, freed me to think about working for Leprosy – this time, for real. I contacted a few agencies, including LEPRO and AIFO. I am presently in touch with them and taking help from the wonderful people working in these institutions to make my working for the cause a reality. In fact, the year 2013 has been a turning point in my life. When I dropped in to spend half a day at the Bangalore office of AIFO at the invitation of Mr. Jose M V, I felt I had come home at last. Jose and Dr. Mani welcomed me as if I were a long lost family. Dr. Mani had prepared a presentation for me about the situation in Assam. I was appalled at the real situation – there seems to be so much work to be done! The meeting was educative, and my resolve to be here for this work became stronger. Earlier I

would keep telling myself, 'If I die without doing this work, I will never forgive myself'. I do not want to die without doing the work for which I was born. I am sure; I was born to work for this cause. I want to be used up, in any and every way possible for making the work of creating dignity for people who suffer from this illness become a reality, and to help others understand that this is just another disease which is curable.

Of course, all through the years, I kept following up with the stories on leprosy, including studying the statistics on the disease – a few years ago, it seemed to me that without me being involved, everything is going well – that the world in general and India in particular has been successful in eliminating this disease, and that everyone, meaning the public in general is well aware about this

being a simple disease that is highly curable. Yet, I remember when in 2001 I was taking printouts about some stories on leprosy – I was doing my academic studies on the subject, secretly patting myself that I was being true to what Mahatma Gandhi said, that 'An ounce of practice is worth more than tons of preaching', that I am indeed being 'involved'. I remember I had left the printouts near my bed. Then revulsion took over – I felt I had 'dirtied' my bedside by having these prints next to it! In the next thirty seconds I was shaken up by the irony of it all, and by the joke – it was a printout and not even someone with the disease besides my bed. And the irony that me, who was a carrier of this disease was reacting so sharply!

My physical leprosy got cured long ago. I was stuck mentally being sick, for decades. I want to help others not take all that long.

Jayashree PK



Collaboration with GLP-WHO:
Dr. N.Manimozhi AIFO – India Medical Coordinator Attended to a consultation meeting with Programme managers from EMRO – Eastern Mediterranean Region in developing a document for Assessing IEC methods, as Temporary Advisor for the RD – SEARO in collaboration with members from LEPRA Society and TLMI . The delegation team consisting of Dr. V.K.Pannikar

Former Team Leader GLP WHO, Mr. Viswanathan GLP WHO Dr. G. Rajan Babu, Ms. Nikita Sarah Singh, Dr.P.V.Ranganadha Rao and Dr. N.Manimozhi was lead by Dr. Suman Barua

During the Consultation meeting there were presentation made by the team related to Assessment of IEC, discussions followed by group work in formulating a concept note to develop the document.



North East NLEP :

Dr. Giovanni, Dr. Jose and Dr. Lanong held discussions with the State Leprosy Officer Assam – Dr. Hazarika, during which operations of AIFO, developments and improvement was detailed. Issues related to the future support form ILEP to Assam NLEP was also discussed.

Borgang Catholic Hospital: the staff, students and patients gave a warm welcome to the delegation

while Dr. Giovanni conveyed the greetings from Italy specially to all the patients who underwent Reconstructive Surgery. Sr. Ancy and Mr. Biswanath Mohanto explained the developments and services rendered to people and the programme. And the tour programme ended with a visit to the state of Meghalaya discussing about the NLEP along with the State Leprosy Officer.



Andhra Pradesh NLEP

Kurnool district: Dr Giovanni, Dr. Jose and Dr. Manimozhi during their visit to the District of Kurnool held meetings with the District Leprosy Officer – Dr. Raja Subba Rao, regarding NLEP collaborations with Kurnool Medical College – Community Medicine/ Microbiology department. Issues related to CBR, Leprosy Control, Training programmes, RCS to formulate working document and Proposals for projects was initiated with the guidance of Dr. Giovanni.

The Principal – Prof. Dr. G.V. Ramprasad welcomed the team and facilitated a meeting involving the Ortho, Dermatology, Paediatrics, and AIFO delegation to look into Academic and Expertise development in the field of Leprosy and CBR.

Prof Dr. Mrs Sridevi Community

Medicine along with her Staff, Intern's and Students had an interactive session with AIFO delegation team discussing issues related to AIFO operations, Leprosy, CBR in the Department of Community Medicine during which Prof Dr. Srinivas from the Department of Microbiology had also participated. In his remarks he highlighted about the Continued Medical Education that took place-thanking AIFO for its involvement and support which was one full day programme exclusive for leprosy which resulted in realization of "Community – Microbiology.

The visit of Dr. Giovanni as an international expert to our programmes had given a boost and importance and had improved towards better working conditions.



This is one of the most important and difficult moment in the life of the Association, because the challenges of the international environment, primarily the global financial crisis, and specifically from the world of international cooperation, this change, require us to rethink our work on all levels: political, managerial and operational. It is not a question of "doing better" but of making radical changes and consolidating the efforts, to ensure that AIFO be able to address these challenges.

In summary, by the end of 2013, the Coordination offices must be able to work independently and have reached the following objectives, - Officially registered in the country with the same mission and vision of AIFO, further promote the image of AIFO at national and international level. - to raise funds locally and develop project proposals for donors. -to review the Country Programme in the light of the new role of the Coordination



From AIFO India Dr. Jose M.V, Dr. Manimozhi Natarajan, Dr. Jayanth Kumar and Mr. Nyjil George participated in all the three events held at Agra India from 24 to 30th November 2012. The CBR congress was organised by WHO and other UN bodies, CBR network, Mobility India, CBM, Sight Savers, and many other national and international organisations. There were about 1200 delegates from various countries participated in the 3 days congress. The pre congress workshop titled “CBR and intellectual disability” and the post congress workshop title “Going beyond taboos” was organised and conducted by AIFO in collaboration with WHO (DAR), CBR network, IDDC, DPI and other international organisations. In both the events, nearly 200 participants from 22 different countries participated in both

pre and post congress workshops. The workshops were facilitated using the participatory methodologies such as small Group discussions, round table interactions, audio-video presentation and discussions, presentation of life stories/case studies and interactions etc. Both the workshops concluded with a outcome that to continue the follow up of workshop (sharing of information and learning together) for which participants details were collected and will be shared by the workshop coordinators.





A five members delegation team (Dr. Renato, Dr. Janice Kooper, Ms. Recardia, Rev. Boima, Mrs. Mavi) from AIFO Liberia visited AIFO India projects between 1st of December to 9th December 2012. The main purpose of the visit was to share experiences, exchange information and learn together on implementation of AIFO supported project activities in India and in Liberia. Dr. Jose, Dr. Manimozhi, Dr. Jayanth and other AIFO team members organised different activities and coordinated the week long programme. Malavalli project field (DPOs, SHGs, PWDs families, school resource center in the village), rural center for the disabled people, School for the blind, Sumanhalli leprosy rehabilitation center, feedback and interactions with the Indian team, visit to district disabled welfare office, meeting with the disability

commissioner Shri.Rajanna, felicitation programme by the Amici trust are the major events organised for the visiting team to have exposure on Indian situation and context. In all the places/discussions The delegates have shared their experiences in Liberia and appreciated the activities organised for their visits. There were also some clarifications on sustainability of the institutions, rights based approach in CBR, documentation, training and follow up in CBR, role of DPOs and SHGs in CBR etc. Both the team members discussed all such issues and clarifications were sought. The Liberia team have extended thanks to the AIFO Indian office for their efforts in organizing the various activities and expressed future collaboration of “South to South” so that a continuous learning take places between India and Liberia.



Fight against discrimination

Discrimination due to leprosy is a disgrace
Treat them with dignity.

* A cause for Leprosy

On every last Sunday of January each year (27th January 2013) Anti Leprosy Day is observed through out the world, and in India January 30th Martyr's Day (Death anniversary of Mahatma Gandhi our Father of the Nation is observed as Anti- Leprosy Day, and as a part of NLEP (National Leprosy Eradication Programme) activities various programmes are carried out throughout the fortnight, with focus on diminishing Stigma and Discrimination and by providing the Dignity and Rights Persons affected by leprosy are denied

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