

Working Together for a World Without Leprosy
By Dr Sunil Deepak, President Elect, ILEP

Dear Friends,

I am honoured to speak to this congress of International Leprosy Association on behalf of International Federation of Anti-leprosy associations or ILEP. I am Dr Sunil Deepak the new President elect of ILEP, I shall be succeeding Mr. Terry Vasey, who is the present of ILEP at the end of this year. The title of my presentation today is Working Together For a World Without Leprosy, which represents the common goal adopted by ILEP member organisations following the last ILA congress in Beijing.

This presentation on behalf of ILEP will be made in three parts -

- ◆ Working Together - this part will explain the sense of different member organisations of ILEP, which work together as a federation
- ◆ For a world without leprosy - this part will touch on the different strengths and activities of ILEP for reaching this goal of a world without leprosy
- ◆ and, Challenges for the future - this part will briefly look at the future challenges as seen by ILEP member organisations.

ILEP Members organisations collaborate through the co-ordination mechanisms of the Federation which are unique in the world of non-governmental organisations. These co-ordination mechanisms ensure that synergies in the field activities of ILEP members and help in avoiding duplication of activities. At the same time, these mechanisms are useful in identifying uncovered gaps and geographic areas for future activities of the member organisations.

The ILEP member organisations work together with all those who share their common goal of a world without leprosy, both in the North and South of the World. These include:

- ◆ Volunteers and donors both in the countries where ILEP members are based and in developing countries where projects are carried out
- ◆ Technical experts
- ◆ Governments and local partners
- ◆ International partners

ILEP is a federation, which was created in 1966 and at present it is formed by 16 autonomous anti-leprosy organisations.

- In 2001, ILEP member organisations supported leprosy related activities in 94 countries in the world
- ILEP organisations raise funds from the public or through institutional funding
- Some ILEP member organisations are secular and others have a missionary background
- Together these autonomous members represent various focuses, interests and priorities for leprosy related activities
- The ILEP members have different governance, set-up and working procedures
- Individual ILEP members are also quite different in their financial strength, which means that there are large difference in yearly support to field activities, which vary from 50 000 - 13 M US \$)

The combined effort of ILEP Members as a Federation is greater than the sum of their individual efforts.

ILEP member organisations work together with a huge number of unpaid volunteers - both in their own countries and in developing countries through their projects. In the ILEP organisations these volunteers are often involved in management Boards, in fund raising, in awareness raising activities, etc.

Majority of the funds collected by ILEP member organisations come from their own home countries but many ILEP members are also involved in raising funds in the countries where they are active. For many ILEP members, over the recent years, institutional funding through governments and foundations has become an important part of their fund collection.

The main underlining characteristics of the activities of the ILEP organisations is the spirit of solidarity and brotherhood and sisterhood with persons affected by leprosy and poor and marginalised population groups for working together in partnership, without any discrimination on the basis of religion, caste, race, political affiliations, etc. with the objective of improving the lives of affected persons and marginalised population groups in the context of human rights.

ILEP organisations have a tradition of high calibre health and social professionals at home and in the field many of the previous and present ILA members have played an important role in the activities of ILEP. Many ILEP member organisations are collaborating with researchers in universities and research institutions, with the aim of improving our scientific knowledge about the disease and its effects on affected persons

ILEP as a federation has an independent Medico-Social Commission for providing technical advise to the member organisations. In addition, many of the ILEP Members' have their own Medical and technical Boards for monitoring and supporting their own field activities.

ILEP members work together with different partners to ensure the maximum support to leprosy affected persons. These include National programmes at different levels, national levels, state, province, region or district levels, under the framework of national leprosy programmes, All leprosy workers, Local grass-root organisations, communities, non-governmental organisations and projects - the NGO partners of ILEP members are both secular organisations as well as missionaries and religious organisations involved in health and leprosy fields, Organisations of affected persons, individual affected persons and their families

Among all the different partners, collaborations of ILEP members with Governments and national programmes have become especially significant and important over the last decade.

ILEP as a federation collaborates with different international organisations, most important being WHO, ILO and UNICEF. ILEP is in official relationship with WHO. At the same time, ILEP as a federation and at the level of individual member organisations, works in collaboration with other international development organisations, like the members of IDDC, which is the consortium of NGOs involved in disability. Collaboration with organisations of persons affected with leprosy like IDEA, Morhan, Handa, etc. is also increasingly more important for different ILEP members. Finally ILEP as a federation and as individual members collaborates with different international professional bodies like ILA, International Union of tuberculosis and lung diseases, etc.

ILEP Members have a vision of a world where the rights of every person affected by leprosy to receive appropriate treatment and rehabilitation are fulfilled, and where all people affected by leprosy are able to participate as fully as they choose at every level of society. ILEP Members are committed to work together to achieve their common goal **of a world without leprosy.**

Between themselves ILEP Members raise and distribute annually around 60 Million US \$ for leprosy, health care and rehabilitation related activities. ILEP Members are involved in most countries where leprosy exists and where people affected by leprosy need help: in 2001 they were supporting 1184 projects in 94 countries - in 2001, there were 403,846 new cases of leprosy diagnosed in projects and programmes receiving some support by ILEP member organisations. 70% of grants earmarked for field activities are allocated to 13 key countries with large numbers of leprosy affected persons to be detected and treated or in need of rehabilitation/care 5% of cumulated expenditure spent for scientific research

There is a qualitative dimension of the support provided by ILEP organisations, which provide support through financial resources, technical support, training courses and international training institutions, human resources, materials, equipment and drugs in a spirit of partnership with National Governments and local partners, in the context of respect of basic human rights.

The commitment of ILEP member organisations is based on a holistic global vision of persons affected by leprosy, keeping in mind their local social and cultural context. Thus for leprosy programmes, ILEP members support activities related to diagnosis and treatment of the infection, which remains as the main priority for ILEP members but they are also involved in supporting activities for prevention of disabilities, medical rehabilitation, support for orthotics and prosthetics, socio-economic rehabilitation, awareness-raising, research, training, etc.

ILEP Members are committed to integration of leprosy related activities in the general health care system and in primary health care systems. Some times, this integration comes through combining one or more vertical programmes to the leprosy programmes, especially for activities related to fight against tuberculosis and Buruli ulcer. Some of the specific activities for promoting integration by ILEP member organisations include:

- Supporting the capacity of governments to provide leprosy treatment and care through primary health care services to achieve increased effective coverage of the population
- Promoting social and economic assistance to people affected by leprosy in particular through linkage with general rehabilitation services and community based rehabilitation
- Ensuring an effective referral system into the general health services
- Providing training and teaching materials for general health workers

ILEP Members' long-term common target is to identify all people affected by leprosy and to ensure provision of appropriate services for them as early as possible in a long-term and sustainable way. This will be achieved by:

- ✓ Having a holistic approach and diversifying activities (combined programmes and other health problems)

- ✓ Being responsive to the needs of governments and local partners:
- ✓ Focusing on Training support for national managers, leprosy programme staff, PHC staff and the provision of teaching materials
- ✓ To strengthen Leprosy expertise within districts/regions/countries
- ✓ Supporting multi-sectoral community-based approaches, which make best use of locally available resources and expertise.
- ✓ Setting-up of clear and simple monitoring systems

As far as the future challenges are concerned, I shall like to briefly highlight three specific areas in which we are involved as a federation as we believe these will have a key role in promoting long-term, integrated and sustainable solutions to the problems related to leprosy -

- ◆ Changing relationship with persons affected with leprosy - from care-receivers to partners in defining priorities and strategies
- ◆ Community-based, multi-sectoral strategies: promoting empowerment and self-sufficiency
- ◆ Networking with non-leprosy organisations, networks involved in development and health issues

ILEP's greatest strength is the diversity of its member associations, each of whom works autonomously in areas of their own interest, and at the same time, agrees to follow up the co-ordination mechanisms of ILEP to use their energies for common goals. The federation has a whole has some common structure like the ILEP office in London, the standing committee and different commissions like the medico-social commission, but all the field and research activities are carried out by individual member organisations of ILEP.

We believe that by working together with governments and all the other national, local and international partners and persons affected by leprosy in an integrated and sustainable manner, ILEP's commitment to *work for a world without leprosy* will be a reality one day. It may yet be a long fight and ILEP members underline their commitment to support this long fight.

There is a long history of positive collaboration between ILEP and ILA and we do hope that collaboration will continue for reaching our common goal of improving the lives of affected persons. On behalf of the Federation, I bring you the greetings of all the ILEP member organisations for a fruitful congress. Thank you for your attention.