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Report on the

Programme managers meeting on leprosy elimination

Beirut, Lebanon
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CONTENTS

1. INTRODUCTION

The World Health Organization (WHO) Regional Office for the Eastern Mediterranean organized a regional meeting of national leprosy programme managers in Beirut, Lebanon, from 15 to 16 December 2010. The meeting was attended by national leprosy programme representatives from Afghanistan, Egypt, Islamic Republic of Iran, Iraq, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Saudi Arabia, Syrian Arab Republic, Sudan, Tunisia and Yemen; representatives of the International Federation of Anti-Leprosy Associations (ILEP); nongovernmental organizations working in some countries of the Eastern Mediterranean Region; representatives of the Global Leprosy Programme; representatives of The Nippon Foundation; and experts on leprosy from the Region as well as from outside the Region.

The objectives of the meeting were to:

- review the progress of the national leprosy elimination programmes during 2009–2010 at the country level;
- discuss the implementation of the Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011–2015) and its updated operational guidelines for subregional planning;
- address the strategic and operational needs at the country level for 2010–2011 operational plan development.

The meeting was opened by Dr Riadh Ben-Ismail, Regional Adviser, Tropical Diseases and Zoonoses, WHO Regional Office for the Eastern Mediterranean, who delivered a welcome note from Dr Jouad Mahjour, Director, Communicable Disease Control, WHO Regional Office for the Eastern Mediterranean. Dr Myo Thet Htoon, Team Leader, Global Leprosy Programme, then welcomed the participants. The opening session ended with the election of Dr Ali Jaber (Lebanon) as Chairperson and Dr Mohammed Salah El Tahir (Sudan) and Dr Abdelaziz H.M. Alahlafi (Libyan Arab Jamahiriya) as Rapporteurs. The programme of the meeting is detailed in Annex 1 and the list of participants is given in Annex 2.

On the second day of the meeting, a special ceremony was attended by Dr Hussein A. Gezairy, WHO Regional Director for the Eastern Mediterranean; Dr Bahij Arbeed, Representative of His Excellency Dr Mohammed Jawad Khalife, Minister of Public Health of Lebanon; and Mr Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination and Chairman of The Nippon Foundation. These guests highlighted the leprosy situation in Lebanon, in the Region and globally, the collaboration between WHO and The Nippon Foundation, and important initiatives related to leprosy: the importance of fighting stigma and the need to defend the rights of people affected by leprosy.

In his address, Dr Gezairy noted that several countries of the Region were in a complex emergency situation that prevented the proper application of control strategies against leprosy. This situation required special efforts to be implemented and maintained in order to make progress in leprosy elimination. He highlighted the problems of stigma and discrimination for leprosy control efforts and asked the participants to adapt the new guidelines to strengthen participation of persons affected by leprosy in leprosy services as

soon as they were finalized and to translate them into action in their respective countries. He suggested that the national leprosy programmes report annually on their progress in implementing the global strategy in their countries. He drew attention to the recent establishment of a sentinel surveillance network for monitoring drug resistance in leprosy and expressed hope that more eligible countries from the Region would apply to join this network. He thanked all partners for their continuous support to the regional programme, and closed with a special tribute to The Nippon Foundation and to the efforts of its founder Mr Ryoichi Sasakawa and the WHO Goodwill Ambassador for Leprosy Elimination, Mr Yohei Sasakawa.

Dr Arbeed in his speech noted that there has been a tremendous decrease in the global disease burden, whereby from 5.2 million cases reported in 1985, the reported number decreased to 805 000 in 1995, then to 753 000 cases in 1999 and to 213 036 cases in 2008. In Lebanon, the numbers were limited to 26 cases being treated in Al Waleed Hospital in the Syrian Arab Republic, with the Ministry of Public Health providing 52 million Lebanese pounds to secure treatment and accommodation for those patients. He stated that Lebanon was one of the countries that had committed to the globally endorsed strategy for leprosy elimination. He closed by acknowledging the efforts of all global partners, particularly WHO and Novartis, which provided therapeutic medicines free of charge.

In his address, Mr Sasakawa noted the active role of civil society in the Region, including nongovernmental organizations, in providing care for the health of the people. He stressed the importance of maintaining vigorous efforts even after the “elimination of leprosy” in order to achieve further reduction in the number of patients. He highlighted the problem of stigma and discrimination, saying that until the removal of the stigma and discrimination that continued to impact the lives of people affected by leprosy and their families, there would be no genuine liberation from leprosy. For this cause, leprosy partners had worked together to arrive at the unanimous passing of a resolution to eliminate stigma and discrimination against people affected by leprosy and their families in September of this year at the United Nations Human Rights Council. The resolution had since been submitted to the United Nations General Assembly for endorsement. Referring to the enhanced global strategy, he noted that it emphasized the active role to be played by people affected by leprosy and their families in fighting stigma and discrimination. He closed by expressing his willingness to provide any assistance requested in his capacity as WHO Goodwill Ambassador for Leprosy Elimination.

The attendance of these three guests provided great support to the national leprosy programme managers and to the meeting. Many of the points raised in the special session were discussed later and contributed to the recommendations of the meeting. The guests also attended the technical session following the special ceremonial session where they shared in discussions that had a large input to the meeting.

2. TECHNICAL PRESENTATIONS

2.1 Global leprosy situation

Dr Myo Thet Htoon, Team Leader, WHO Global Leprosy Programme

During 2009, 244 796 new cases of leprosy were diagnosed. Of the WHO regions, the South-East Asia Region reported the largest number (166 115), followed by the Region of the Americas (40 474), while the Western Pacific Region (5243) and the Eastern Mediterranean Region (4029) had the lowest numbers. Generally, there has been a decrease in newly reported cases in the past few years; however, in the Eastern Mediterranean Region, some increase took place in 2007 and 2009, which was due to more reporting of cases from southern Sudan. Sixteen countries worldwide reported 1000 or more new cases between 2005 and 2009. Of these, the highest number of new cases was from India (133 717), followed by Brazil (36 535) and Indonesia (17 260). Sudan, from the Eastern Mediterranean Region, reported 2100 new cases in 2009. The total number of new cases with grade 2 disabilities was 14 320 in 2009. The regions reporting the highest number of grade 2 disabilities were the South-East Asia Region (7286) and the Region of the Americas (2645). India and Brazil alone contributed to about half of the global newly reported cases with grade 2 disabilities.

Much progress has been achieved worldwide since the introduction of multidrug therapy (MDT). Nearly 16 million people affected by leprosy have been diagnosed, treated and cured. There has been an increased coverage of MDT services to underserved populations and it is estimated that disabilities have been prevented in 3 million individuals. Awareness of the disease and the political commitment of national authorities towards leprosy have increased. Human rights issues related to leprosy patients have started to become emphasized on agendas of international agencies and national authorities. Leprosy has been integrated into the national health policies of many countries. Thanks to agreements between WHO and The Nippon Foundation between 1995 and 1999, and then later with Novartis, MDT drugs have been offered free of charge to all leprosy cases worldwide since 1995. Leprosy has become a success story of effective partnerships between countries, international agencies and other stakeholders.

Challenges and opportunities vary according to type of area.

- Areas with high disease burden, with high numbers of untreated and hidden cases and high number of new cases with grade 2 disabilities, and/or high number of children new cases. There is a need to establish a sustainable leprosy control programme that can offer treatment and supportive services to handle all new cases. In this area, case-finding will be mainly based on voluntary reporting; however, in special situations a rapid screening of the population may be carried out to find any undetected cases. There is also a need to examine household contacts on a voluntary basis.
- Areas with low disease burden, where several high-endemic countries became low-endemic countries. There is a need to apply a focused needs-based strategy taking into account:
- task-oriented training for peripheral health workers;

- strategically locating services to ensure they are accessible to patients;
- establishing referral facilities to ensure quality of care and treatment of complications.
- Underserved population groups. There is a need to develop innovative and practical strategies involving operational solutions. Partnerships with community and local health volunteers need to be applied. Also capacity-building of local health workers and community-based organizations is needed.
- Urban areas. There is a need to focus mainly on slum areas where inequalities are highest. Leprosy needs to be an integral part of urban health services. Public–private partnerships need to be expanded. Correct information needs to be disseminated utilizing appropriate media. Access to referral services for special care needs to be ensured.

In discussions following the presentation it was mentioned that Brazil is the only country that did not achieve the global elimination target (one case or less per 10 000 population).

2.2 Highlights in implementing the enhanced global strategy

Dr Myo Thet Htoon, Team Leader, WHO Global Leprosy Programme

Leprosy elimination faces many challenges, including access to diagnostics and treatment services, effective referral services, supportive supervision, monitoring, effective IEC to increase community awareness, capacity-building, reaching out to underserved populations and creating effective partnerships.

For access to diagnostics and treatment services, there is a need to strengthen integration of leprosy control services, ensure all new patients are timely diagnosed and treated, that treatment is made available near to home, and that the MDT supply chain is well maintained.

For effective referral services, there is a need to link them to quality of care, whereby difficult to diagnose cases, cases with complications and cases needing rehabilitation are referred to the most suitable service. Also there is a need to integrate leprosy services into existing basic services; this integration will help sustain these services. The referral network needs to be established at primary, secondary and tertiary levels of care. Lastly, referral services need to be accessible.

Supportive supervision needs to be regular and integrated, and health workers need to be trained in this. Monitoring should include timely and regular reports, analysis of data and feedback on reports. Effective IEC should include selecting the most effective messages, using the most cost-effective media, both printed and electronic, and identifying sustainable IEC activities.

Capacity-building is important to maintain expertise in the field under various disease endemicity. It should be based on training need assessment that takes into consideration various categories of health workers involved in the leprosy control programme. It also needs to be integrated into other programmes, medical colleges, paramedical training institutes and other allied professionals.

Reaching out to underserved populations should be based on the principal of equity. For sustainability of such services, innovative and collaborative efforts are needed. For creating effective partnerships, organization of persons affected by leprosy is important to improve leprosy services. Also, there is a need to involve community-based organizations in supporting leprosy services at the grass-roots levels.

2.3 Improving early case-finding and treatment

Professor Yasin Al Qubati, WHO Temporary Adviser

The WHO definition for early case-finding is diagnosing a leprosy case and giving proper treatment before the start of nerve impairment. It is clear that nerve impairment is the result of delay in diagnosis. Delay is defined as the time elapsing between the appearance of the first symptoms (which depends on the patient's awareness), the detection of the patient, i.e. diagnosis, and the start of treatment. The delay can be:

- patient delay: before awareness of the condition and after awareness of the condition; or
- health service delay, which can either be a delay in diagnosis or a delay in treatment.

This definition has no specific timing and ignores the delay that does not result in impairment. Causes of delay are multiple and may be due to social and religious beliefs; traditional healers; weak health systems resulting in wrong diagnosis; or delayed referral. The patient may have been slow to seek help. Early diagnosis refers to diagnosis before the appearance of early signs and symptoms of nerve involvement.

Delayed diagnosis leads to nerve function impairment; disabilities; higher stigma; isolation; more chance of disease transmission; higher incidence and prevalence; and difficulty in reaching elimination goals. Delay in diagnosis may be because the patient is afraid of the diagnosis and of the consequences of the disease, such as isolation and rejection. The community may also be responsible for a delay, through lack of support for the patient. The disease itself also has an element of responsibility owing to its bad reputation and lack of acute signs and symptoms. Health providers also may be responsibility for delay by considering the disease to be of low priority and by encouraging the high visibility of poor treatment outcomes and low visibility of good treatment outcome.

Health education is needed to change the attitude of the community towards the disease; to encourage clients to seek help; and to develop the skills and awareness of health service professionals. Health education should lead to an increased capability to recognize the early signs of leprosy, to seek timely diagnosis and to start treatment. The following are requirements for health education:

- training of health care providers to aid early diagnosis and treatment at the primary level;
- mass media, especially television, are the best health education methods for communities;
- health education may also take place in community gatherings and during surveys;
- health services need to be patient friendly, affordable and accessible;

- patient contacts also need to receive health education;
- cured patients may help in health education;
- health education needs to be maintained;
- groups that require health education include school pupils and personnel; university students; traditional healers; pharmacists; and religious leaders.

One of the most important messages of health education is that a single dose of anti-leprosy drugs will kill a very high percentage of the viable *Mycobacterium leprae* bacteria. Accordingly, patients become non-infectious once they start treatment.

2.4 Improving community awareness of leprosy

Dr Christine Schmotzer, Aid to Leprosy Patients

It is noted that case detection of leprosy continues to fall, that numbers of relapses remain low, with a slightly rising trend, and that some countries report a disability rate of 20% or more among new cases. The new global target, according to the Enhanced Global Strategy for Further Reducing the Diseases Burden due to Leprosy (2011–2015), is to reduce the grade 2 disability rate per 100 000 population found among new cases at the beginning of 2011 by at least 35% by the end of 2015.

Early case detection is an important element in future leprosy control. The Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011–2015) warrants efforts in early case-finding. In low-endemic countries, community awareness is essential for early case-finding. Awareness is defined as “consciousness about a piece of information or a matter”. Awareness is more than knowledge; it is supposed to prompt “action”. Community awareness must be carried out in a culturally acceptable manner. It is recommended that leprosy awareness is raised within the context of improving skin health and skin care. Care must also be taken to ensure that referral links and accessible high-quality leprosy services are in place before raising awareness. Countries are encouraged to develop a package of basic dermatology for primary health care, with leprosy being an essential component of the package. National resource centres should maintain and enhance knowledge and clinical skills for leprosy management; train dermatologists, primary health care staff and community workers; provide tertiary-level care for complicated leprosy cases; provide quality assurance; and provide slit skin smear services.

2.5 Capacity development strategy in leprosy control: training needs analysis

Dr Charles Phaff, Netherlands Leprosy Relief, Mozambique

Training needs analysis is the first step in the development of a national leprosy capacity development strategy. It is an essential step for effective training programme planning. It consists of a systematic analysis of national leprosy control at all levels. It has six phases: context analysis, capacity needs inventory, performance analysis, training solutions, training programme and management arrangements.

Context analysis results in an assessment of the current country capacity on leprosy control/care service delivery and main capacity concerns. The process of context analysis involves information on quality and quantity of leprosy control, institutional assessment, main concerns on human resources, staff turnover and transfer, and experiences on capacity development.

The second phase is capacity needs inventory, which covers job descriptions, organization and management needs, and Ministry of Health needs. The result is an inventory of technical, organizational and management requirements for effective service delivery.

Performance analysis covers staff organization and staff quality issues. The result is an analysis of good performance and a priority list of management actions to improve staff performance, and training/learning needs for various levels.

Training solutions involves capacity development support and training strategy. The result is a description of the leprosy training packages in the country. It may involve learning methodologies such as distant learning, face-to-face, real life and joint learning. International expertise may be needed to implement these learning methodologies.

The training programme covers the annual training programme, ad hoc training, trainer accountability and training evaluation. The result is a comprehensive and budgeted annual training programme.

Management arrangements cover integration in the Ministry of Health and training needs analysis committees. The result is training programmes towards improved leprosy control services that are integrated in the overall management of the Ministry of Health.

2.6 Capacity development strategy in leprosy control

Dr Charles Phaff, Netherlands Leprosy Relief, Mozambique

We need to know why capacity development in leprosy is necessary and what exactly the problem is.

The problem is that general health workers are not able to diagnose certain skin manifestations of leprosy and therefore cases may be overlooked and diagnosis delayed. Thus it is necessary to build capacities of health care workers to be aware of early skin lesions associated with leprosy in order to be able to diagnose these cases once they present to the health care service. The Enhanced Global Strategy for Further Reducing the Diseases Burden due to Leprosy (2011–2015) states that “There is an urgent need to build and sustain leprosy expertise at country level. A strategy needs to be developed in collaboration with partners that will cover training programmes at global and national levels”.

Furthermore, the problem of capacities is increasing as leprosy is becoming a relatively rare, low-priority disease. This requires special efforts to maintain the necessary level of clinical and programmatic skills in health staff. As the leprosy problem decreases in size, staff

skills decrease due to fewer cases encountered and lower priority. At a certain time the disease may start to increase in the community again, owing to the decline in staff skills and misdiagnosis of cases. Therefore, the key message is that maintaining a sufficient number of effective professionals is crucial for leprosy control and care, and that a sound and sustainable leprosy capacity development can ensure this.

Development of national capacities can be carried out at three levels: institutional or ministry level; organizational or leprosy control programme level; and human resource development or individual level. Institutional level development is characterized by a broad context, for example ministries of health, finance, planning and education; WHO; ILEP; patient organizations, etc. It is a long-term process with various dimensions, such as harmonization and coordination and exchange of knowledge and experience. It follows norms, laws and values.

Organizational development is carried out by the national leprosy control programme and involves efforts to obtain political commitment, partner support, systematic and regular supervision, and career development. Human resource development involves planning in advance and includes training as a continuous process. Who to train, what to train, how to train and where to train in relation to practice are all specified.

3. COUNTRY PRESENTATIONS

3.1 Afghanistan

Dr Mohammad Salim Rasooli

The national leprosy programme in Afghanistan is structurally integrated into the national tuberculosis programme at the Ministry of Public Health. Leprosy services have been present since 1960 when the German Medical Services organization took care of leprosy cases. Leprosy Control, a German nongovernmental organization only active in Afghanistan, began its efforts in 1984 and is now in charge of high-quality leprosy services in the country. In 1998, WHO supported the programme to establish a leprosy clinic in Maiwand Hospital to diagnose and treat leprosy cases. Leprosy is integrated within the dermatology service at the governorate level.

The cumulative number of registered cases from 2001 to 2008 was 334. There were 52 new cases in 2009. Achievements of the programme include:

- development of the strategic plan (2009–2010) as well as leprosy guidelines;
- training more than 120 health workers;
- procurement of one vehicle for the programme;
- integration of the national leprosy programme into the national tuberculosis programme;
- increasing case detection from 21 in 2006 and 32 in 2007, to 36 in 2008 and 52 in 2009;
- developing a training module;
- printing IEC material.

Challenges include:

- lack of resources due to neglect and low priority;
- leprosy control not being fully integrated in the Basic Package of Health Services system;
- political instability and lack of security, for example the programme vehicle was bombed and partly destroyed;
- very poor infrastructure plus difficult geographical terrain, leading to very difficult accessibility and a poor communication system.

3.2 Egypt

Dr Sameeh Galal

The national leprosy control programme in Egypt is responsible for policy-making, planning, training, technical supervision, evaluation and reporting. It works through an integrated leprosy–dermatology programme in partnership with national and international agencies, including WHO, GLRA and other nongovernmental agencies. In 2009, there were 700 new cases; of these 6.3% were disability grade 2. Case detection decreased progressively from 1567 new cases in 2000 to 700 in 2009, and case detection rate per 100 000 population decreased from 2.45 in 2000 to 0.97 in 2009.

Achievements in 2010 include:

- conducting comparative operational research, comparing two approaches to improve case detection among contacts;
- initiating community participation in six governorates;
- training doctors on WHO guidelines on management of reaction cases;
- establishing a referral centre for severe reaction cases in the delta region, and intensifying capacity-building programmes for medical and paramedical personnel.

Future plans include:

- improving case detection, compliance to MDT treatment and reaction through home visits, health education and defaulter tracing;
- preventing disability by maintaining a good quality of service for ulcer care, physiotherapy and eye care;
- strengthening the community participation programme.

Challenges include:

- not achieving the prevalence rate target at district level, where five districts in two Upper Egypt governorates (Qena and Sohag) had a prevalence rate of more than one per 10 000 population in 2009;
- not having a referral centre for severe reaction cases in Upper Egypt;
- a need to decrease stigma and social discrimination through improving community awareness.

3.3 Islamic Republic of Iran

Dr Mahshid Nasehi

The prevalence rate of leprosy in the Islamic Republic of Iran has decreased progressively since 1994 when MDT was introduced and was 0.01 per 10 000 population in 2009. A total of 45 cases were under treatment in 2009. In that year there were 32 detected cases and the case detection rate decreased progressively to 0.04 per 100 000 population. Most new cases were in urban areas (72%). New cases were evenly divided between males and females. All new leprosy cases were 15 years of age or above. More than half the new leprosy cases had disability grade 1 and 39% had disability grade 2. The incidence rate of grade 2 disability decreased from 0.041 to 0.017 per 100 000 population in 2009. Most of the new leprosy cases in 2009 were multibacillary (88%); 70% of the multibacillary cases detected in 2008 completed their treatment. In 2009, eight new leprosy cases were among Afghans living in the Islamic Republic of Iran.

The main strategies used in the national leprosy programme are: improving case-finding by increasing the knowledge of physicians and the general population and conducting Leprosy Elimination Campaign (LEC) and Special Action Project for Elimination of Leprosy (SAPEL); and treating patients with MDT, and rehabilitating disabled cases through physical and social rehabilitation services.

The 2011 action plan includes:

- improving public knowledge and attitude through: producing an educational film and adverts for television and radio; designing and printing educational posters; installing public billboards; and producing pamphlets and booklets for patients and their families;
- holding workshops and seminars for leprosy programme coordinators, physicians and disease-control staff; training health care workers, laboratory technicians and welfare and rehabilitation staff; advocacy and social mobilization; special case-finding activities; rehabilitation; and monitoring and evaluation;
- field visits, nominal registration, data analysis in two annual reports, establishing confirmatory mechanisms for relapses.

The main challenges facing the programme in the Islamic Republic of Iran are: insufficient compliance of some patients due to the side-effects of drugs; insufficient physical and social support for disabled patients from organizations; illegally entering Afghans; and social stigma.

The discussion following the presentations raised the need to confirm that the disability grading system used for reporting in the Islamic Republic of Iran conforms with the WHO standard grading system used in other countries in order to make comparisons possible.

3.4 Iraq

Dr Sabah Mahdi Abd Al Aema Jawad Al Hamza

The cumulative number of notified leprosy cases in Iraq is 62, of which nine cases are still alive. These nine cases are aged between 60 and 90 years and all are without disabilities. During the past two decades only two cases have been detected. MDT is available free of charge and the rate of treatment completion is 100%.

The main challenges are:

- lack of familiarity with the disease among physicians in general, and dermatologists in particular;
- the insecure situation in the country hampers leprosy surveillance activities;
- social stigma related to leprosy is high.

During the next year, there are plans to improve the knowledge and awareness of technical staff and physicians, to produce educational information and to broadcast this through the media.

The discussion following the presentation raised doubts regarding the very low numbers of detected cases and it was suggested that investigations should be conducted to verify the situation.

3.5 Lebanon

Dr Ali Jaber

Lebanon is a low-prevalence country for leprosy. Detected leprosy cases are sent to a dermatologist at the American University of Beirut for diagnosis, confirmation and therapeutic prescription. Other cases go to El Waleed Hospital in the Syrian Arab Republic where they receive medical and social care. In 2009, 29 cases were registered for care in the Syrian Arab Republic. No new cases were detected in 2010. The Lebanese Government pays US$ 1200 each year for care of these cases in the Syrian Arab Republic.

Most of the 29 cases come from Akroom, a town near the border with the Syrian Arab Republic. Although no new cases were detected in 2010, further investigation is required to find out if there are hidden cases in that town. The objective in the near future is to further reduce the prevalence of leprosy by 2015 by:

- increasing awareness among health personnel;
- educating the community and fighting social stigma;
- early detection of hidden cases;
- rehabilitating patients;
- maintaining 100% coverage with MDT.

The plan for leprosy services in Akkar (a district in the North Governorate, which includes the town of Akroom), includes three levels of service.

Level 1 services will be provided by peripheral units or health centres. These will detect and refer suspected leprosy cases, provide MDT, treat minor reactions and provide health education.

Level 2 services will be provided by the referral integrated unit (Caza Hospital). This hospital will diagnose and treat cases; refer uncomplicated cases to level 1 for MDT; diagnose and treat reactions; provide health education and counselling; and direct socioeconomic rehabilitation according to local circumstances.

Level 3 services will include referral units with specialized clinical, surgical, ophthalmological and neurological services. These units will develop workplans; give technical support; supply MDT; monitor the leprosy situation at country level; coordinate efforts with partners and neighbouring countries; and provide capacity-building.

3.6 Libyan Arab Jamahiriya

Dr Abdelaziz Alahlafi

From 2001 to 2010, there were a total of 66 detected cases of leprosy. There are 6–8 new cases per year. Most are male (80.3%). Non-Libyans constitute 28.8% of cases.

The national leprosy programme's achievements in 2010 included:

- a focused needs-based strategy;
- accessible service points;
- holding four training workshops, with international trainers invited to a workshop held on 23 January 2010 in Sirt city;
- examining household contacts of cases.

Future plans and targets include:

- carrying out case-finding campaigns;
- reassessing leprosy-related disabilities;
- implementing the Enhanced Global Strategy for Further Reducing the Diseases Burden due to Leprosy (2011–2015);
- developing an operational plan;
- undertaking research to improve diagnostics.

Challenges include:

- poor case-finding activities and the need to reaffirm commitment;
- the need for information, education and communication (IEC) materials to promote voluntary reporting;

- the national leprosy programme suffers from low priority due to other high priorities such as HIV and tuberculosis; this can be addressed by fostering WHO support to advocate for stronger commitment;
- the need to collaborate with partners to cover training needs with respect to disabilities;
- the need to have a unified national registry to ensure quality and validity of information.

During the discussion it was suggested that next year's meeting could be held in Tripoli, Libyan Arab Jamahiriya, in order to support the programme and advocate for a higher priority for leprosy.

3.7 Morocco

Dr Abdellatif Idrissi Azzouzi

There were 41 new cases of leprosy in 2009, with 14.6% grade 2 disability in new cases. Both detection rate and prevalence rate decreased progressively from the early 1990s until the first half of 2010. The leprosy programme strategy for 2008–2012 includes three elements: decentralization and integration of leprosy services; response to other needs in public health dermatology; and development of dermatology services.

The general objective of the leprosy programme at the end of the strategy in 2012 is to reduce the case detection rate of grade 2 disabilities by 50% of the baseline prevalence of 2009. Operationally, implementation will include:

- examining contacts of 75% of multibacillary cases;
- training 90% of health workers in endemic areas;
- improving the referral system;
- developing surgery for nerve damage and disabilities.

Challenges include:

- sustaining services as leprosy is becoming low priority;
- creating new partnerships;
- reducing stigma;
- training health care workers;
- providing surgery for disabled cases.

3.8 Oman

Dr Mahmoud Al Sekaiti

Oman is not endemic for leprosy, although in the past it was considered a health problem in the country. Leprosy used to be a priority health problem due to the large number of expatriates coming from high-prevalence countries. MDT was implemented in Oman in 1992 and since then the epidemiological situation has changed; leprosy was eliminated in 1998 and is no longer a health problem. In 2009, eight cases were registered, of whom two were Omanis and six were non-Omanis. In 2010, until early December, six cases were

detected, of whom two were Omanis and four were non-Omanis. Until early December 2010, eight cases were registered for treatment.

The national leprosy programme activities include:

- organizing workshops;
- producing a leprosy manual;
- establishing a central registry with a cross-indexing system;
- 100% coverage by MDT;
- having a good surveillance system for early recognition and management of leprosy;
- having a well-developed referral system and professional and political commitment.

The leprosy control programme has special action projects: SAPEL, LEC and Leprosy Elimination Monitoring (LEM). The main challenge is to maintain the achievements reached so far.

In the discussion, it was recommended that Oman treats non-national leprosy cases in a similar way to Saudi Arabia, where non-national cases are treated and are no longer deported.

3.9 Pakistan

Dr Chris Schmotzer

Pakistan is a low-prevalence country for leprosy. The disease was eliminated in 1996 but there were 527 new cases registered in 2009, while 865 were registered for treatment. The prevalence rate was 0.54 per 10 000 population and the incidence rate was 0.33 per 10 000 population. Grade 2 disability was still around 20% of new cases, indicating the need for improving early case-finding. The main case-finding is by dermatologists. Nongovernmental organizations mainly carry out leprosy control activities. Leprosy control is combined with primary health care, tuberculosis control, physical therapy and dermatology at the provincial level. Leprosy services are combined with basic dermatology in “skin camps”, where patients are screened for skin diseases and their awareness is raised. Ten skin camps were conducted in 2009; 4086 persons were screened and 31 leprosy cases were found.

In a strategy combining leprosy detection with basic dermatology, primary health care staff are trained in detecting skin conditions, including “suspect leprosy”. An IEC programme is conducted via lectures and orientation courses to medical, nursing and paramedical staff. In addition, lectures on leprosy are delivered to schools during eye health screening programmes. Anti-leprosy drugs are provided free of charge by WHO and are distributed to leprosy centres through nongovernmental agencies. Local social welfare services cooperate with nongovernmental agencies such as GLRA to provide services and supplies. The government contributes salaries, infrastructure and medicines.

Future plans include:

- strengthening the two national referral centres;

- developing an appropriate human resource structure;
- promoting a basic dermatology package within primary health care.

Challenges include:

- reaching appropriate coverage;
- maintaining expertise in leprosy;
- improving networks with dermatological services.

3.10 Saudi Arabia

Dr Naila Anwar Abuljadayel

The national leprosy programme operates alongside the national tuberculosis programme, through the same administrative structure. Fifteen new cases were detected in 2009, 10 of whom were Saudi Arabian while five were non-Saudi Arabian. Total new cases have progressively decreased from 1995 (121 cases) until 2010 (15 cases). At all times, there have been more male than female cases (in 2009 the ratio was 11:4).

The discussion following the presentation highlighted the important point that non-national detected cases received full treatment and that the new Ministry of Health rules stated that there should be no forced deportation of non-national cases. This point was highly appreciated by the participants and it was recommended that countries that still apply a policy of deporting leprosy cases should change their regulations in accordance with Saudi Arabia.

3.11 Sudan (northern)

Dr Mohammed Salah Eltaher

There were 814 new cases detected in 2009, of which 19.6% were disability grade 2. Some localities did not achieve the target of a prevalence rate less than one per 10 000 population. Khartoum state had the highest number of registered cases as well as cases with disability grade 2 in both 2009 and 2010 (until June).

The many achievements include:

- implementing the programme in all states, even in areas that were considered inaccessible, such as Kurmok in Blue Nile, Kapcapia in North Darfur, and Jabal Marra in West Darfur;
- reducing stigma;
- improving the cure rate;
- reducing disability grade 2, which denotes early case detection;
- nongovernmental organizations providing housing to ex-leprosy cases;
- celebrating National Leprosy Day in Mayo with participation of partners;
- organizing several training courses and providing supervision in many areas that were previously inaccessible.

Future strategies include sustaining all leprosy activities, including early case detection, prompt treatment, reduction of disability grade 2 by 35% by 2015, supervision and monitoring, and carrying out research.

Future challenges include:

- sustaining programme activities;
- increasing priority at the Ministry of Health;
- creating strong partnerships;
- integrating activities into primary health care;
- reducing stigma by health education (using television, radio, community awareness, posters, etc.);
- validating data;
- contact tracing;
- community-based rehabilitation and reaching the target of elimination in all localities;
- improving monitoring and evaluation, increasing visits to special areas;
- internal and external training;
- maintaining a regular MDT supply;
- carrying out applied and operational research and developing a programme for dealing with disabilities and rehabilitation.

It is concluded that leprosy is still a health problem, stigma and disability are still high and there is a need to include rehabilitation as a clear element in future plans.

3.12 Sudan (southern)

Dr Callixte Minani

Arkangelo Ali Association activities in southern Sudan include:

- case-finding;
- socioeconomic rehabilitation of affected cases;
- reconstructive services;
- assessing leprosy-disabled people;
- providing footwear when needed;
- conducting in-service training to health workers;
- teaching self-care to people affected with leprosy;
- distributing seeds and fishnets as methods of socioeconomic rehabilitation;
- supporting affected people through income-generating activities.

Arkangelo Ali Association leprosy centres in southern Sudan cover more than 1 million people and are distributed in four states: Lakes (four centres, covering 220 945 population), Warrap (two centres covering 251 814 population), Western Bahr El Ghazal (two centres, covering 151 320 population) and northern Bahr El Ghazal (two centres, covering 474 138 population). There were a total of 769 new cases in 2009 and 493 new cases in 2010 until June.

Constraints in leprosy activities include:

- the wide geographic area needing to be covered;
- high stigma;
- lack of skilled staff;
- lack of IEC material;
- poor road network;
- insecurity in some areas;
- slow integration of leprosy into primary health care;
- few partners in leprosy control;
- lack of trained physiotherapists;
- absence of a footwear workshop in the areas covered.

Achievements include regular supply of free MDT, training activities by the national programme, as well as development of leprosy policy and guidelines. However, the threat of war between northern and southern Sudan endangers these efforts.

Future challenges include:

- the need to continue surveillance and training at all levels of personnel;
- the need to train at least two Sudanese doctors in leprosy surgical techniques;
- eye care needs;
- health education;
- cataract surgery facilities;
- revival of the footwear workshop in Agok-Wau;
- integration of the leprosy programme into newly opened tuberculosis centres.

3.13 Syrian Arab Republic

Dr Kinaz Cheikh

There are very few leprosy cases in the Syrian Arab Republic. Only two cases were reported in 2010 until mid-December. Both cases were female; one had disability grade 2 and one was a relapse case. The prevalence rate is 0.001 per 10 000 population. Cases are diagnosed and treated at Al Waleed Hospital. The national leprosy programme has an objective of decreasing the prevalence to below 0.001 cases per 10 000 population and to decrease grade 2 disabilities among new leprosy cases.

Challenges include:

- late diagnosis;
- relapse cases;
- weak supervision;
- lack of training.

There is a need to:

- develop educational materials;
- increase knowledge of physicians, health care workers and the general population;
- train tuberculosis centre staff;
- strengthen cooperation with dermatology services;
- obtain funding to achieve the above-mentioned needs.

3.14 Tunisia

Dr Latifa Maazaoui

Tunisia is a country with a low prevalence of leprosy. There are one or two cases per year. The Ministry of Health has set the objective of eliminating the disease by 2015.

The national leprosy programme strategy includes:

- early detection of cases;
- free treatment;
- follow-up;
- prevention of handicaps;
- rehabilitation.

The national leprosy programme coordinates with Tunisian nongovernmental agencies against leprosy. It is responsible for epidemiological surveillance, drug management, etc. At the provincial or regional level, primary health care workers are responsible for follow-up activities and epidemiological surveillance. At the district or local level, the centres are responsible for case detection, distribution of medicines, survey conduction and following-up cases. Health education, social support and treatment of disabilities are carried out in collaboration with Tunisian nongovernmental agencies against leprosy. Detected cases are confirmed at the reference centre in Sfax.

3.15 Yemen

Dr Abdul Rahim Al-Samie

There were 554 new cases in Yemen in 2000 and this number decreased to 387 in 2009. The detection rate also decreased from 3 per 100 000 population in 2000 to 1.7 per 100 000 population in 2009. The prevalence rate decreased from 0.3 per 10000 population in 2000 to 0.19 per 10 000 population in 2009. There was 6.7% disability grade 2 among new cases in 2009.

The general objectives of the programme are to sustain and strengthen quality leprosy services all over the country, to sustain the interventions for the prevention and management of disabilities, and to provide social and economical rehabilitation for patients affected by leprosy. Specific objectives are to:

- reduce stigma;
- improve the MDT cure rate to 95%;
- integrate care into general health services;
- collaborate with partners;
- ensure political commitment and early case detection;
- increase access by expanding leprosy control activities.

Future challenges include:

- maintaining current efforts without relaxation;
- improving passive and active case-finding and examination of contacts;
- skin surveys;
- case-holding;
- rehabilitation;
- training;
- intensifying health education;
- maintaining community participation by integrating people affected with leprosy into the community;
- monitoring, supervision and evaluation.

4. GROUP WORK DISCUSSIONS

4.1 Group 1: How to avoid delay in diagnosis (early case-finding)

Afghanistan, Egypt, Sudan, southern Sudan, Yemen
Facilitator: Professor Yasin Al Qubati

Delay in diagnosis can be categorized in three phases:

- time from patient awareness of symptoms until the moment he or she asks for help;
- time needed for the health facility or health provider to diagnose the case;
- time between diagnosis and start of treatment.

Avoiding delay requires:

- increasing community awareness of early signs and symptoms of leprosy using IEC materials;
- conducting short health awareness seminars for health care providers;
- defining and establishing a functional referral system.

Awareness sessions should target health care providers, traditional healers, pharmacists and drug sellers, and community leaders. Weaknesses in health care staff may be due to their ignorance about leprosy, lack of self-commitment to leprosy or leprosy phobia, and lack of resources to diagnose and treat leprosy cases. Most of these problems can be solved by regular, multicategory training.

There is a reciprocal relationship between stigma and delay in diagnosis and treatment, with stigma leading to delay and vice versa. Stigma can be measured in patients, health care providers, traditional healers, drug sellers and community figures. It can be addressed by formulating a questionnaire to measure the stigma in each of these groups and then formulating a solution according to the information collected.

4.2 Group 2: Improving community awareness of leprosy

Islamic Republic of Iran, Iraq, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Saudi Arabia, Syrian Arab Republic, Tunisia
Facilitator: Dr Chris Schmotzer

There is a need to raise community awareness of leprosy. The general population can be given training on skin health (e.g. washing; using oil for dry skin; misuse of cosmetics and corticosteroids; skin lesions; how to reach health services). If possible, this should be integrated into existing health care programmes. Health care workers can be trained to look for signs and symptoms of leprosy and can be instructed in the referral system. Community leaders can also be trained and regularly visited. Patients and close contacts can be encouraged to work as volunteers for finding suspected cases and for referring them.

Medical and paramedical students also need to be trained and there should be mandatory training course for the most relevant specialties (i.e. dermatology and infectious diseases) for the diagnosis of leprosy cases. Leprosy experts also need to be maintained in the field. Non-medical people, for example leprosy cases, their family members, teachers and scouts, need to be trained to become case finders. Posters and educational materials need to be produced and distributed and photographs of well-known people may be included in these materials to make them more popular and attractive.

A potent referral system is a prerequisite for improving community awareness. A referral system with a feedback mechanism will stimulate community awareness and improve cooperation. Efforts to combat stigma and discrimination also need to be supported. Counselling, patient education and improved confidentiality are also important elements. The actual name of the disease need not be used, according to the cultural situation.

5. CONCLUSIONS

According to the discussions that took place in the meeting sessions, and as guided by the addresses of the Regional Director for the Eastern Mediterranean and of Mr Sasakawa during the special session, some issues were identified as important issues that can contribute to the recommendations. In this respect, participants stressed the importance of early case-finding and early treatment, and that efforts should be taken to minimize the delay in case-finding.

It was acknowledged that some countries in the Region had taken the initiative to stop deporting leprosy-affected non-nationals and that those countries provide these cases with a

full course of MDT. It was also noted that some countries use a disability grading system that is different from the WHO standard system for leprosy disabilities. The meeting also recognized the problem of maintaining expertise and skills related to leprosy diagnosis and treatment, especially in low-burden countries. It was noted that some countries showed a marked decrease in cases within a short time; this may be due to an actual decrease in the number of cases or to decreased case-finding.

Fighting stigma remains an important issue related to leprosy and its cases. Efforts have been made by Mr Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, as well as by WHO, to defend the rights of persons affected by leprosy and to combat stigma using different strategies. It was highlighted that leprosy programmes suffer from low priority and accordingly lack of funds and many programmes complain of constrained budgets to carry out effective activities.

Countries in the Region vary in their burden of the disease and in their experience related to leprosy; accordingly, some countries may benefit from the experience of others. It was agreed in the meeting that the Enhanced Global Strategy for Further Reducing the Diseases Burden due to Leprosy (2011–2015) will be the reference document for guiding leprosy programmes in the coming five years.

6. RECOMMENDATIONS

To Member States

1. Dermatologists and other concerned health workers should be trained and continuously kept aware of leprosy, especially in low-endemic areas. It should also be ensured that dermatologists are linked to leprosy services.

2. All new leprosy cases should be properly assessed for disability at diagnosis and after completion of treatment according to the standardized WHO criteria, in order to ensure standard disability reporting is fulfilled in all settings, and that a quality indicator of the programme is introduced.

3. Member States should guarantee that once leprosy cases are diagnosed, they should receive free treatment, regardless of their nationalities, as long as they reside in the country.

4. Efforts should be made to investigate reasons for delay in detection of late-detected cases, in order to understand barriers causing delayed detection and to develop appropriate solutions.

5. National programmes should include leprosy workplans in the next round of joint operational planning with WHO (2012–2013).

6. Efforts should be made to conduct proper investigations, including active case-finding and contact tracing, especially in areas where new leprosy cases have declined dramatically, in order to confirm the lower incidence status or to discover hidden cases that were wrongly interpreted as declined incidence.

7. National programmes need to begin involving people affected by leprosy in the improvement of leprosy services, in raising awareness, in advocacy for rights of affected persons and in stigma reduction.

To WHO

8. The Regional Office needs to explore additional resources in support of the regional leprosy programme. This will subsequently be reflected as support to the national leprosy programmes. As one of the strategies to raise resources, it is suggested that a donor meeting should be organized back-to-back with the next regional programme managers meeting on leprosy elimination.

9. The Regional Office should coordinate an interprogramme exchange of experiences between different Member States as one of the strategies to maintain expertise in the Region.

10. The Regional Office should organize a regional consultation to adapt the Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011–2015) to the regional context.

Annex 1

PROGRAMME

Wednesday, 15 December 2010

09:00–09:30	Opening session Welcome note (*Dr J. Mahjour*) Note by Dr Myo Htoon, Global Leprosy Programme, Regional Office for South-East Asia Objectives of the meeting Introduction of participants (*Dr R. Ben-Ismail*) Election of Chairman and Rapporteurs
10:00–10:15	Review of agenda
10:15–11:00	Global leprosy situation (*Dr M. Htoon*)
11:00–12:45	Regional leprosy situation: country presentations (Islamic Republic of Iran, Iraq, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Saudi Arabia, Syrian Arab Republic, Tunisia) (*country representatives*) *Discussion*
13:45–14:15	Technical presentation on improving early case-finding and treatment (*Dr Y. Al Qubati*)
14:45–16:00	Two group work sessions (on early case-finding and improving community awareness)
16:15–16:45	Group work presentations and discussion (*Plenary*)
16:45–17:00	Wrap up of first day (*Rapporteur*)

Thursday 16 December 2010

09:00–09:45	Special ceremony, followed by side meeting) Address by Dr Hussein A. Gezairy, Director, Regional Office for the Eastern Mediterranean Address by His Excellency Dr Mohammed J. Khalife, Minister of Public Health, Lebanon Address by Mr Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination
10:15–11:00	Highlights on Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011–2015) (*Dr M. Htoon*)
11:00–12:30	Regional leprosy situation: country presentations (Afghanistan, Egypt, Pakistan, Sudan, southern Sudan, Yemen) (*Country Representatives*)
13:30–14:30	Introduction to capacity development strategy in leprosy control (*Dr C. Phaff*)
14:30–15:30	Highlights on the guidelines for training needs analysis (*Dr C. Phaff*)
16:00–16:30	Conclusions and recommendations
16:30	Closing session

Annex 2

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