

FOR THE ELIMINATION OF LEPROSY

A MESSAGE FROM THE SPECIAL AMBASSADOR

Where Is the Sense of Urgency?



Visiting a colony in Orissa, India

Last year, as WHO special ambassador for the elimination of leprosy, I made three visits to India, and also went to Madagascar and Angola. I wish to express my heartfelt appreciation to the people I met for their dedicated efforts. Nevertheless, frankly speaking, I strongly feel that a sense of urgency is lacking. We have only two years left in which to achieve the goal of elimination. A lot more needs to be done.

I am urging everyone concerned, from political leaders and medical officers to health workers out in the field, to share their know-how and experience, and maximize their efforts for elimination.

As I repeatedly say, on a journey of 100 miles, after 99 miles we are only just halfway. We have the chance to rid the world of a scourge that has been with us for millennia, yet we are only halfway there.

In order to accomplish the historical achievement of elimination by the end of 2005, the year 2004 will be of crucial importance. Unless we all do our best, this goal will be impossible.

In order to increase public awareness of leprosy, I have been working hard to drive home to political leaders, government officials, journalists and people in general the following three messages: leprosy is curable; free treatment is available; and social discrimination has no place. With these words to guide us, let us go forward together and complete the rest of our journey.

Yohei Sasakawa
WHO Special Ambassador
President, The Nippon Foundation

Leprosy is Curable.

Free Treatment is Available.

Social Discrimination has no Place.

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Prescriptions for Success

With the goal of elimination set for the end of 2005, we asked four public health experts to take a moment and tell us how they view the current situation and what they feel needs to be done to make elimination a reality.

Awareness and Easy Availability of MDT Are Key Dr. A.K. Choudhary



Leprosy has been a public health problem in Bihar for many years. The Indian government launched a National Leprosy Control Program in 1955. In 1983, with success of MDT (multidrug therapy) in treatment of leprosy, the program was renamed the National Leprosy Eradication Program (NLEP). The infrastructure was further expanded to deliver leprosy services under two World Bank-supported projects from 1994 to 2000 and 2000 to 2004.

In addition, from 1998 to 2003, four Modified Leprosy Elimination Campaigns (MLEC) were successfully conducted in Bihar. As a result, the leprosy prevalence rate has been reduced significantly from 52 per 10,000 in 1996 to 4.8 per 10,000 in November 2003.

There are a number of specific factors that need to be urgently addressed. These include continuing the intensified effort toward community awareness, especially among women and underprivileged groups; providing annual orientation for general healthcare staff to sensitize them for leprosy work; improving coverage of MDT services beyond the government health setup; and strengthening sub-district supervision and monitoring of NLEP activities.

Awareness and easy availability of MDT are the key to leprosy elimination. With this in mind, we can consider the following innovative approaches: active involvement of Panchayati Raj (local self-government) institutions at panchayat and village level; involvement of private medical practitioners from all systems of

medicine in providing wider outreach for identification/diagnosis and treatment of leprosy; making panchayat members, local public representatives and opinion-makers responsible for leprosy elimination at panchayat/village level; and involvement of all medical colleges and district-level hospitals for reconstructive surgery.

Dr. A.K. Choudhary is Health Secretary for the Government of Bihar, India

Elimination Is Only an Intermediate Goal Dr. Pieter Feenstra



Now that leprosy has been placed high on the agenda of health ministries in leprosy-endemic countries, not only has the prevalence rate been reduced but as a result of improved and intensified leprosy services and the wide availability of MDT, an increasing number of cases are being found and treated.

Despite these impressive results, however, the achievement of the elimination target is only an intermediate goal and the struggle against leprosy will have to be continued for many years to come. We must also accept that in a few countries, whether at the national or sub-national level, it will not be possible to achieve the target before the end of 2005 because of the high incidence of the disease. These countries should not be discouraged, but be stimulated and supported to sustain the fight against leprosy.

The best and most effective tool we have is to diagnose leprosy in a timely manner and treat it with MDT. Therefore diagnostic and treatment services have

to become accessible to all communities in areas where leprosy occurs. This is to be achieved by effectively integrating leprosy services within the general system, which is already the major element of WHO strategy.

Even after the elimination target has been reached, these services have to be sustained. Moreover, childhood vaccination with BCG must be continued, as this reduces the risk of developing leprosy. In addition, chemoprophylaxis, which is currently under study in several trials, promises to become an important tool in the elimination of leprosy.

Dr. Pieter Feenstra is Senior Advisor for Public Health, Head, Leprosy Unit, Royal Tropical Institute (KIT), Amsterdam, The Netherlands

Integrate Leprosy as Health Unit Activity

Dr. Francisco Songane



Over the past several years, the Mozambican government has intensified efforts to eliminate leprosy. Good collaboration between the Ministry of Health and various partners has been fundamental in making tools and funds available to win this battle. The important and valuable contribution of these partner organizations has been vital to countries such as Mozambique that would otherwise not have had the possibility of meeting the 2005 target.

In spite of the fact that the leprosy burden is related to poverty and a low level of development, we have obtained some success not only with MDT but also with the easy clinical assessment that eliminates the use of laboratory skin smears.

We launched two elimination programs in 1999 and 2000 for sensitizing and mobilizing communities for early detection and treatment; moreover, the most peripheral and endemic areas started to focus on important issues such as education of local authorities and training of health staff.

In this way, we are working to improve case-finding and eliminate the stigma of leprosy by explaining that the problem has a solution and treatment is free.

To achieve the 2005 goal, it is important that leprosy elimination be integrated as one of several activities in the health unit. Therefore, we will continue to train peripheral staff in order to have at least one trained person in each unit and three community volunteers in each village to search for leprosy and see that patients complete their treatment. Reinforcing the link between health units and villagers through community councils should be a priority.

Innovative steps that should be taken include working with other important sectors that are well-placed in rural, peripheral and remote areas, such as the Ministry of Agriculture through its rural field workers;

employing the Myanmar concept of training Mother and Child nurses in leprosy case-finding; and linking treatment with a food kit to benefit patients, who are normally poor, and so improve passive case-finding.

Prevention of deformities is another priority, through the project of training general physiotherapists countrywide. Using handicapped people to make shoes for leprosy patients is one unconventional idea that is already in place to reintegrate patients with deformities.

Dr. Francisco Songane is Mozambican Minister of Health.

Sensitize and Mobilize Local Communities

Professor Andry Rasamindrakotroka



Since Madagascar implemented the Leprosy Elimination Program in 1992, results have been encouraging, even though we have not yet reached the elimination target set for 2000. That is why we developed an intensified elimination plan covering the period 2001–2003.

The implementation of leprosy elimination campaigns (LEC) and special action projects (SAPEL) in 1997–1998 allowed us to detect and treat many hidden cases in highly endemic areas. One of the weaknesses of the program was the difficulty of obtaining reliable epidemiological data because of the lack of follow-up of newly detected cases. The situation worsened in early 2002, due to political events that brought activities to a complete stop and negatively affected the intensified elimination plan. Activities resumed in mid 2002, including training of health workers and updating of registers.

The following factors should be taken into account if elimination is to be achieved: training of health workers in prompt diagnosis and correct case management at all levels of the health system to ensure reliable data; strengthening of information, education and communication (IEC) activities to sensitize patients to get diagnosed early; improving collaboration between private and public health centers; and setting up an efficient communication system to ensure the smooth flow of information.

There is also a need to bring the health system nearer to the population through the establishment of Mobile Health Teams to reach remote and land-locked areas. Twelve teams have been active since the end of 2003, and 12 more are expected to join them this year. Also, there is a need to ensure patients comply with the cure regimen by sensitizing and mobilizing local communities and providing them with appropriate logistical support, such as bikes and motor bikes.

Professor Andry Rasamindrakotroka is Madagascar's Minister of Health and Family Planning.

Leprosy Elimination—Progress and Prospects

Dr. S.K. Noordeen



With under two years until the World Health Assembly target date for the elimination of leprosy by the end of 2005, Dr. S.K. Noordeen looks at what has been achieved so far—and what still needs to be done.

Progress toward elimination of leprosy in the last two decades has been phenomenal. This has

largely been attributable to two factors—the development of multidrug therapy (MDT) and its implementation on a wide scale, and the commitment of leprosy-endemic countries to eliminate leprosy as a public health problem as reflected in the World Health Assembly resolution of May 1991.

The World Health Assembly resolution was largely the result of the recognition of the tremendous potential of MDT and the worldwide interest in trying to see the end, at least in public health terms, of a disease crippling millions of individuals.

MDT as recommended by WHO has proved to be therapeutically highly effective in curing leprosy. Cure rates have been close to 100%. Relapses have been extremely infrequent. Drug resistance has not been a problem. MDT acceptance levels have been very high.

The perception that leprosy can be cured through MDT has resulted in considerable reduction in social stigma attached to the disease. MDT implementation has also motivated health workers and has facilitated integration of leprosy work within the general health services. Above all, the effectiveness of MDT and its potential to contribute to elimination of the disease has enabled extraordinary donor support for free supply of MDT drugs to the patients.

Channeled through WHO, this support has enabled universal coverage for treatment of leprosy patients through standard high-quality drugs. Such visible 'drug security' has strongly contributed to the sustained commitment of national governments toward leprosy elimination.

Prevalence Rates Down Significantly

The overall global reduction in prevalence over the last 18 years has been very striking, with the disease burden coming down by 90% (5,369,000 cases in 1985 to 524,000 cases in 2003).

With regard to progress in the African continent, the results seen in several countries have been exceptional.

Between 1985 and 2003, the reduction of prevalence in Africa has been 95% (from 1,028,000 cases to 50,000 cases) while in other parts of the world (mainly Asia and the Americas) it has been slightly less at 89% (from 4,341,000 cases to 474,000 cases). Even in very high prevalence areas, the prevalence reduction has been steep.

However, there have been some exceptions, particularly in countries where medical service coverage has been quite poor and where the programs have been hampered due to civil disturbances. Even now, the leprosy situation is not entirely clear in a small number of countries affected by civil strife (e.g. Somalia, Democratic Republic of Congo, Sierra Leone and Liberia).

Looking at what has been achieved in the past year, there has been a reduction of about 19% in both prevalence and new case detection globally. This has been contributed largely by India and Myanmar, where the reduction in prevalence has been 22% and 39%, respectively. In terms of new cases detected, the reduction in India has been about 23% and in Myanmar, 24%. If the progress made by India in the past year is maintained, then there is every possibility it will meet the elimination target set for 2005.

In other high-burden countries, progress has been less dramatic. The situation in Brazil continues to be unclear both in relation to prevalence and case detection, and is in urgent need of clarification. However, the overall trend there is toward steady reduction in the number of advanced cases, cases with deformity and cases among children.

Patchy Geographic Coverage

The continuing problem in achieving leprosy elimination in certain areas is mainly one of coverage. Even now in a number of countries, health services coverage is relatively poor. This means that leprosy patients can only be reached through special campaigns.



Dr. S.K. Noordeen (center) seen with Orissa Assistant State Leprosy Officer Dr. P.K.B Patnaik (right) and Ambassador Sasakawa (far right) during a visit to a village in Orissa.

Plus, even in areas where health services coverage is reportedly high, access to leprosy services remains far from satisfactory. Service providers are not sufficiently proactive and awareness about the disease and its curability is quite low.

This is seen in the trend of leprosy in a number of high-burden countries. While prevalence reduction was very rapid in the initial years after reaching high MDT coverage, the rate of decrease has slowed down considerably in recent years.

New cases continue to be detected, mainly from areas where MDT had been introduced more recently. New cases are also being detected in other areas in significant numbers, due to such reasons as re-registration of old patients and over-diagnosis of leprosy among individuals with only doubtful evidence of the disease, both resulting from the pressure to maintain high levels of case detection.

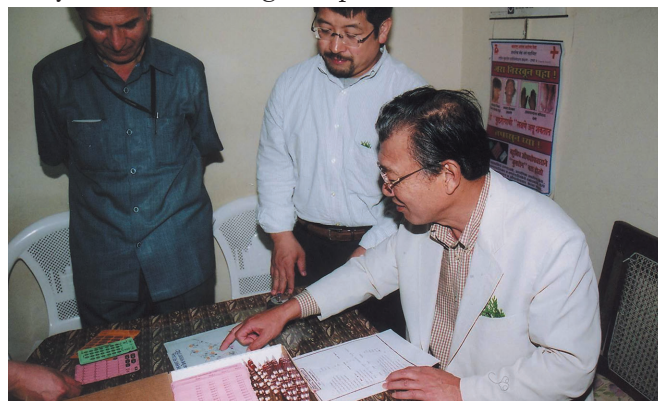
Sustained Interest Needed

Achieving leprosy elimination will depend upon the following factors: sustained interest, advocacy and political commitment at the global, regional and national levels; strengthened support by partners; and the continued intensification of the integration of leprosy work within the mainstream of general health services.

This should make it possible to ensure that all or nearly all leprosy patients are identified in time and treated with MDT, and that patients are accepted within

their communities.

In some areas, leprosy elimination may take longer, in spite of the best efforts being made. This is largely a result of the late start of MDT implementation, unusually high prevalence levels to begin with, and certain unknown epidemiological factors. However, this is likely to apply only in certain limited areas and not likely to influence the global picture.



Checking MDT at a Primary Health Center in Nagpur, Maharashtra

Thus the overall prospects for reaching the leprosy elimination goal appear to be quite bright provided we continue to sustain our commitment, identify problem areas and situations and intensify our efforts as required. □

Dr.S.K.Noordeen is former WHO Director for the Action Program on the Elimination of Leprosy and Chairman of the Leprosy Elimination Alliance, Chennai, India

Union Minister Committed to the Cause

WHO Special Ambassador Yohei Sasakawa found a ready audience when he called on Union Minister for Health and Family Welfare Sushma Swaraj on a visit to India last November.

Mr. Sasakawa began the meeting by outlining his mission to eliminate leprosy and advance the human rights of people affected by leprosy. Mrs.Swaraj responded enthusiastically, saying she takes a keen interest in leprosy issues that goes beyond her formal responsibilities as health minister.

"I believe Mahatma Gandhi when he said that if you want to approach God, you must serve leprosy patients. These people are the most deprived, the ones who have suffered most—not just physically from the disease but also mentally, because they have been rejected by society."



Mrs. Swaraj, who was appointed health minister in January 2003, recalled how her first contact with leprosy-affected people was at the age of 25, when she contested a local assembly election in her home state of Haryana. There was a colony of 90 patients nearby, and she made a point of getting to know them. "In addition to the medical help that the doctors provided, I would visit them every Sunday to socialize and dine with them," she said.

At this colony and at another in South Delhi, she persuaded leprosy-affected people to stop begging for a living and allow the government to care for them. Although she could not persuade their families to take them back, she did help to arrange marriages between them and organize educational opportunities for their children.

"I can assure you that this cause is very dear to me. I am acting out of conviction," she told Special Ambassador Sasakawa. "We must achieve the goal of leprosy elimination by 2005." □

THE SPECIAL AMBASSADOR'S JOURNAL

India

Orissa (July 7-9, 2003)



Residents of a colony in Orissa

In July, I went to the northeastern state of Orissa. After Bihar, it is the state with the highest prevalence rate in India, with 7.3 leprosy patients per 10,000 inhabitants at the time of my visit.

Of Orissa's 30 districts, nine have a prevalence rate of more than 10 per 10,000. Political leaders such as the governor, chief minister and health minister are keenly committed to eliminating leprosy. Meanwhile, integration is moving ahead and MDT is widely available. Nonetheless, in the past 10 years, not much progress has been made. Why?

There are three major problems, the first relating to urban areas, the second to border regions and the third to tribal areas. The prevalence rate in urban areas is more than double that in rural districts, and particularly bad in the urban slums that account for 13% of Orissa's population. Next, 34 of the state's 314 blocks are situated in border areas where patients frequently move back and forth across the state line. For a long time, healthcare services in these rural border areas were inadequate; furthermore, MDT was only introduced to these areas in 1994, and full state-wide coverage wasn't achieved until 1997. Finally, proper information about leprosy is not getting to the tribal peoples who make up 22% of the state's population. Enhancing interpersonal communication programs is crucial to reaching them.

Faced with these adverse conditions, a four-step milestone plan to eliminate leprosy, district by district, before the end of 2005 has been drawn up under Governor M.M. Rajendran. With the governor leading the way, I sense an enthusiasm for the task not seen in other states. I hope that all involved will step up their efforts to make the plan a success.

Visiting a leprosy hospital-cum-colony of about 200 people, I was struck by the fact that there were

young women and children there who are completely cured. That they are living in unnecessary isolation is proof of the social stigma attached to them. In addition to the drive for leprosy elimination, therefore, we need a separate effort to ensure such people can be welcomed back into society.

West Bengal (November 11)

In November, I visited Kolkata, Delhi, Wardha and Mumbai. In Kolkata I went to Garden Reach, an urban slum of 300,000 people with a population density of 30,000 per square kilometer. In the slum clinic I found neatly organized records going back 26 years for as many as 8,000 leprosy patients who had been treated there. I have nothing but admiration for the dedicated efforts of the staff over such a long period. The clinic also acts as an NGO office, and provides micro-financing for people affected by leprosy to help them start their own small businesses. So as well as treating patients, it is also helping them to become self-reliant once they are cured, and as such serves as a very good example of how to encourage social participation.

Elimination activities in West Bengal generally seem to be making good progress, although from what I have seen there are still a few problems. First, there are flaws in the management of MDT. The availability of drug supplies at Primary Health Centers varies, and there are insufficient stocks of children's dosages—a point I was asked to convey to the relevant authorities in Delhi. Second is the problem of defaulters—patients failing to complete treatment. With the integration of leprosy services into the general healthcare system in Kolkata, responsibility for case-holding has passed to local government. As a result, many patients have had to change the clinic where they go for treatment, or have found that they have been inadvertently dropped



Children in Garden Reach, Kolkata

from the treatment list. Clearly, it will be necessary to conduct a review of patients to track down anyone who might have been overlooked in the changeover.

Maharashtra (November 12-19)



A woman learns how to weave at Shantivan Nere, Maharashtra

In the central Indian city of Wardha in the state of Maharashtra is the Sevagram Ashram where Mahatma Gandhi lived from 1936. Gandhi regarded leprosy as a challenge to humanity and was associated with the disease for over 50 years. He once said, "Leprosy work is not merely medical relief; it is transforming the frustration of life into the joy of dedication, personal ambition into selfless service." This place is home to the Gandhi Memorial Leprosy Foundation. Established in 1951, the foundation focuses in particular on education and health training programs in areas where the prevalence rates are especially high. When the foundation began its work, the prevalence rate in Wardha District was 233 per 10,000. Since the introduction of MDT, it has dropped to 3.4 per 10,000.

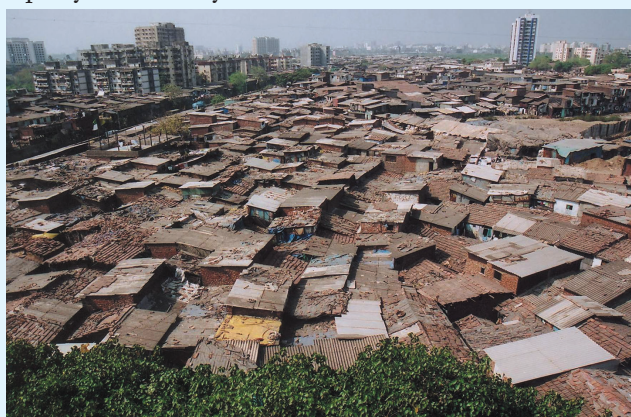
I visited Mumbai from November 16 for four days. Maharashtra has a population of more than 100 million, of whom 42% live in cities, and the rest in 42,000 villages scattered all over the state, many of them in areas that are extremely difficult for the health services to reach. In 1981, the prevalence rate for the whole of Maharashtra was 62.4 per 10,000, but today the figure is down to 2.75. There remain three barriers to elimination: the inaccessible tribal regions and remote areas, the slums that account for 65% of the urban population and the difficulty of keeping track of the movements of people in border areas.

The state is currently promoting a special action plan to address these difficulties. I was very encouraged by my meeting with Chief Minister of State, Shri Sushilkumar Shinde, who told me that both he and the chief secretary have taken it upon themselves to form a committee consisting of state representatives from

education, labor and industry as well as representatives from NGOs to tackle leprosy problems in the state. I also received assurances from State Governor, Shri Mohammed Fazal, and State Health Minister, Shri Digvijay Khanvilkar, of their firm intention to work toward the elimination of leprosy, and verified that the state government is committed to this goal at the highest level. The strategy drawn up by the health ministry has been well formulated, and all that remains is for it to be implemented.

Mumbai is home to Asia's biggest slum, Dharavi. Some 600,000 people from all over India live here, and the population density is as high as 60,000 per square kilometer. The Bombay Leprosy Project has been working here since 1979. In 1983, the prevalence rate in the slum was 22.4 per 10,000; by August 2002, it had dropped to 0.7 per 10,000. This dramatic decrease is thanks to the devoted efforts of project members. This NGO not only seeks out and treats patients; it helps in the socio-economic rehabilitation of leprosy-affected people who have made a complete recovery, with support from local companies offering vocational training.

To clear up society's misunderstandings about leprosy, it is vital to involve the non-leprosy community. I visited the Maharashtra Chamber of Commerce to meet with the president and other officers and ask for their support in disseminating correct information on leprosy to their members. I also had the opportunity to address the oldest Indo-Japanese association in India about my mission. Afterward some young ladies in the audience asked questions such as, "Is it true that leprosy is hereditary?" or "Is it true that leprosy is dangerous because it's a communicable disease?", and I realized that ordinary people still know far too little about leprosy and that much more needs to be done to educate the non-leprosy community.



Dharavi, the biggest slum in Asia

It goes without saying that strong political will, the commitment of all people from central government

officials to local health workers and a feasible strategy are necessary for elimination. But even more important is the necessity to reach out to society, disseminate accurate information and get each person to feel that elimination is his or her responsibility. I have no doubt that India, where Mahatma Gandhi made such a contribution to acknowledging the human dignity of those with the disease, will succeed in eliminating it once and for all.

Cambodia (December 4)



Meeting a patient at Kien Khleang Center, Cambodia

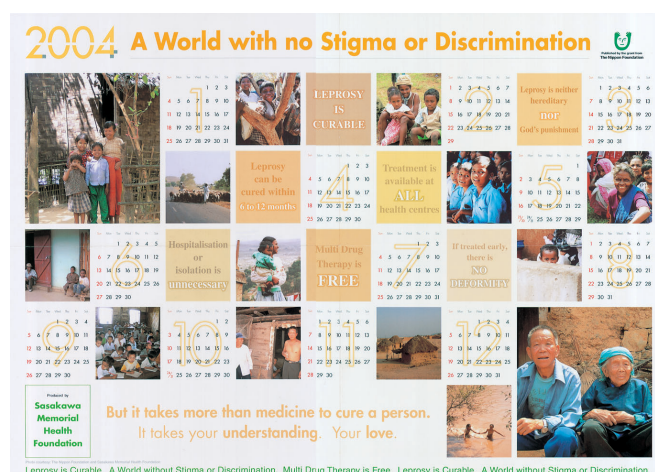
I met Dr. Mam Bunheng, secretary of state for health, at the Ministry of Health in Phnom Penh. Cambodia achieved the elimination target in 1988, and the current prevalence rate is 0.47 per 10,000. Secretary Bunheng told me that in undeveloped areas of the country, particularly the difficult-to-reach mountainous regions, the monitoring system is being strengthened and elimination activities are ongoing. I also had the opportunity to visit Kien Khleang Center, a facility for disabled people offering surgery and rehabilitation. I spoke with about 40 leprosy patients being treated there. The aftereffects of their disease were such that almost all of them required surgery, but with the fine treatment they are receiving from Dr. Stephen Griffiths of the CIOMAL—Comite International de l'Ordere de Malte, the aim is to help them return to society at an early date.

Sustaining what has been achieved and ensuring the social rehabilitation of leprosy-affected people are critical tasks to be continued beyond 2005. The fight against leprosy is never-ending, and I have renewed my determination to devote my life to this battle. □

SMHF Calendar Offer

The Sasakawa Memorial Health Foundation (SMHF) has prepared wall calendars for 2004 and 2005 entitled "A World with No Stigma or Discrimination." The 2004 calendar features messages relevant to the fight against leprosy, such as "Leprosy can be cured within 6 to 12 months" and "Leprosy is neither hereditary nor God's punishment," while the 2005 calendar is based on the Universal Declaration of Human Rights.

The 60cm x 42cm calendars are available free of charge by contacting the SMHF office at 1-2-2 Akasaka, Minato-ku, Tokyo 107-0052, Japan (Fax: +81-3-6229-5388, Email: smhf@tnfb.jp). Please include the words "Calendar Offer" in the subject heading. □



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