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EDITORIALS

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The International Leprosy Association at 50 Years

Fifty years ago, in January 1931, the International Leprosy Association (Association Internationale de la Lèpre) was born as an outcome of a conference organized in Manila by the Leonard Wood Memorial for the Eradication of Leprosy. As stated in the report, "... this Conference afforded an exceptional opportunity to consider the question of a permanent international organization of those engaged in activities concerning leprosy and of others interested in such work. It has long been felt that such a body would serve a useful purpose in stimulating greater interest in the problems and in efforts to obtain more effective results." The first constitution of the International Leprosy Association amplified this, stating that the purposes of the organization were, "to encourage and facilitate mutual acquaintance and collaboration between persons of all nationalities concerned in leprosy work and the coordination of their efforts; to facilitate the dissemination of knowledge of leprosy and its control; and in any other practicable manner to aid in the antileprosy campaign throughout the world; and to this end publish a scientific journal of leprosy . . . (The Association) shall endeavour to cooperate with any oth-

er institution or organization dealing with leprosy work."

Fifty years and eight international congresses later (Cairo, 1938; Havana, 1948; Madrid, 1953; Tokyo, 1958; Rio de Janeiro, 1963; London, 1968; Bergen, 1973; Mexico, 1978), the International Leprosy Association is more alive than ever. It counts some 653 members distributed in 89 countries. The INTERNATIONAL JOURNAL OF LEPROSY, whose first issue was published in 1933, has now for nearly five decades served as a link among leprosy workers throughout the world. It has disseminated knowledge on leprosy, much of it original work, with some 30,030 pages of printed material. We are heading for the Twelfth International Congress, to be held in Delhi in 1983.

On the China Sea, on a side trip taken by the leprologists attending the Manila Conference to visit the Culion Leprosarium in Palawan, what were the dreams and the worries and the frustrations of the "Founding Fathers" of the Association sailing amidst the Philippine islands, drafting the constitution? What are today our dreams, our worries, our frustrations on this fiftieth anniversary?

What is the situation today compared to

the situation half a century ago? No doubt tremendous advances have been made during these five decades in understanding of the disease and regarding its control as well as in care of the patients and attitudes towards leprosy in general.

The two polar clinical types of leprosy, and thereafter the clinical spectrum, have been clearly defined, providing a framework for the further elucidation of the immunological response. The relative infectiousness of the two types of leprosy has been measured by epidemiological studies with the demonstration of the very low infectiousness of the tuberculoid type (which in most parts of the world affects the large majority of patients). This provided the scientific basis for the abandonment of segregation and for the promotion of ambulatory treatment. Sulfone compounds were recognized as effective therapeutic agents, making possible the organization of large scale mass campaigns in many parts of the world. Hence, in countries where at times hundreds of thousands or even millions of persons were suffering from the disease, with the prevalence reaching 2 and 3 percent (or one person in 40), population based control for the majority of patients and not merely treatment for a few could be envisaged. Although every attempt at *in vitro* cultivation or inoculation into animals had previously failed, in 1960, the foot pad technique made possible the inoculation of *M. leprae* into the mouse, opening the way for drug sensitivity assays. The armadillo was discovered as a suitable animal in which to grow large numbers of bacilli, which put the development of a vaccine in the realm of reality. Nude mice have been found to be an alternate animal for collecting bacilli.

More important perhaps, leprosy has become recognized as a common, transmissible disease not to be considered different from any other transmissible disease and which does not call for exceptional measures. The myth of leprosy, this age old psychodrama in which the living healthy were exorcising their fear of death by using the leper as a propitiatory victim, making of him a living dead, has receded all over the world. In some cultural contexts, substituting the eponym Hansen's disease for the biblical term, leprosy, helped to change attitudes. In other cultures, shifting words

has been found unnecessary and even counterproductive.

Segregation, which was common 50 years ago, has been as a practical matter abolished. In most countries, special laws restricting the basic human rights of patients have been repealed. Children born of leprosy patients, who used to be removed from their parents at birth to be placed in foster homes, at times suffering huge mortality, are now more and more left to the care of their parents since an adequately treated leprosy patient presents little or no danger of contagiousness.

As fear of contagiousness receded, deformities came to be more fully realized as constituting the crucial problem in leprosy. In some areas, up to 25% of patients are crippled. While early treatment may prevent the development of deformities, physiotherapy was recognized as an integral part of leprosy care to help those patients who had not been detected at a sufficiently early stage. New techniques of reconstructive surgery were pioneered.

At the same time, it came to be realized that leprosy, like most other health problems, is not solely a medical issue. It is a much broader one, which encroaches on cultural, social, economic, and political issues. Leprosy control is therefore much more than the application of good medical care. Its management requires a multidisciplinary approach, calling on the expertise of specialists from other disciplines such as operations research, management sciences, anthropology, and sociology.

Credit should be given to all those who have worked hand in hand to achieve these successes over the last 50 years: men and women of science and of good will, in the field and in laboratories, at all levels and with all kinds of backgrounds. No names should be mentioned. Some are known, and others are not, which makes them no less important.

If the temptation must be resisted to mention names, perhaps one should, however, stress the roles of some agencies or institutions which over the last 50 years have contributed to make possible these advances.

First, one should mention the Leonard Wood Memorial. The Memorial, jointly with the Leprosy Commission of the Lea-

gue of Nations, was responsible for taking the initiative to convene the Manila Conference in 1931. It was responsible for the creation of the International Leprosy Association, making possible publication of the INTERNATIONAL JOURNAL OF LEPROSY. For many years thereafter, it maintained a vital support to the JOURNAL.

The World Health Organization (WHO), through its Leprosy Unit at Headquarters and its Regional Offices, has played a major role in promoting leprosy control activities as well as research and training. Based on the reports of its Expert Committees, it has established guidelines for leprosy control which have served as a blueprint for the organization of national leprosy control activities by governments as well as for the intervention of voluntary agencies. Members of the International Leprosy Association have regularly served as WHO experts or consultants. The last Expert Committee (Fifth Expert Committee, Geneva, 1976) was chaired by Dr. Stanley G. Browne, Secretary-General of the International Leprosy Association.

Lately, through the Special Programme on Research and Training in Tropical Diseases (TDR), supported by the World Bank and the United Nations Development Program (UNDP), WHO has launched two major research programs. One is IMMLEP, which deals with the immunology of leprosy. Its goal is to make a vaccine. The other is THELEP, which aims at developing new and more effective drugs. It is now realized that advances in research are more than ever the outcome of coordinated team efforts. Members of the International Leprosy Association are participating actively in these programs.

The International Leprosy Association has the privilege of being one of the few scientific bodies with a recognized official relationship with the World Health Organization. This enables the Association to send an observer to the World Health Assembly and to the Regional Committees, thus affording a unique opportunity to influence governments.

In recent years an increasingly important role in leprosy control and care of leprosy patients has been played by the International Federation of Anti-Leprosy Associations (ILEP), a coordinating body of some

24 fund-raising agencies in Europe, North America, and Japan. This organization has contributed outstandingly to promote the dignity of leprosy patients, improve the level of care, strengthen control efforts, and support research. It has called on members of the International Leprosy Association to serve in an advisory capacity on its Medical Commission. ILEP associations have also substantially supported the publication of the INTERNATIONAL JOURNAL OF LEPROSY. In the face of new challenges raised in leprosy control, it can be anticipated that there will be an ever increasing cooperation between ILEP and the International Leprosy Association.

Regarding ILEP, and this is also true for other voluntary agencies involved in leprosy work, large or small, their capacity to be effective requires the participation of the public through donations. This mobilization of public solidarity towards leprosy patients is a new phenomenon which affords broad opportunities but also imposes responsibilities.

This, in a rough and perhaps overly simplified way, is leprosy in the context of 1980.

New problems have arisen, which were not even suspected a few years ago.

First, there is the emergence of strains of *M. leprae* which are resistant to current sulfone therapy. This calls for the design of new treatment strategies, which means much more than just replacing one drug with another. It has important implications regarding the whole management of leprosy control from the organization of services to laboratory support and training. The spread of primary resistance would mean that we are getting back to where we were 50 years ago. It would be a tragedy indeed. The issue of resistance must therefore be faced urgently.

Second, there is a widespread and likely unjustified disillusion with leprosy control as it has been conducted since sulfones became available. Governments are raising doubts about the soundness and feasibility of present campaigns, all the more so because there are many other health priorities in countries where leprosy is endemic. Even UNICEF, which used to provide drugs and vehicles, the bread and butter of leprosy control, has recently reduced or in

some countries discontinued its assistance. The fact is that through the use of dapsone, great expectations were entertained that with treatment for everybody, the disease would be eradicated within a couple of decades. No proper evaluation mechanism had been incorporated in the activities from the beginning with the result that in spite of most encouraging results in a number of countries, people are now questioning the value and even the relevance of leprosy control. This is a lesson on which to meditate: promising too much may have a backlash effect when expectations are not realized.

A third troublesome point involves the integration of leprosy control into basic health services. Everybody realizes that leprosy does not deserve special treatment as far as management of health services is concerned. It should be part of the general health services and should be provided in the context of primary health care. Indeed, it is the best test for primary health care: wherever appropriate leprosy control, with all its present difficulties, can be made available for everybody, primary health care should represent an achievable goal. In countries where control is well organized while health care is rudimentary, specialized services for leprosy should serve as a model and should be used to spearhead development of basic health services. Unfortunately, there is still much resistance to integration and, sad to say, resistance from within the medical profession. In spite of some progress, treatment of patients on the premises of medical facilities or their admission into general hospitals is often resisted. There is also a great danger of using integration as an alibi to reduce support for leprosy control. Actual integration in the field is one thing; integration on paper is another. Leprosy control should therefore be integrated so far as it is possible, practical, and does not jeopardize prospects of success. Patients come first; doctrine comes after.

These are general remarks. Depending on where one stands, what one does, and what functions one has, each of us can perhaps pick up something of interest, some initiative to be undertaken, or some action to be pursued. There are, however, two areas where, I believe, the International

Leprosy Association as an influential body (and let us not underestimate the influence of the International Leprosy Association's membership as a whole) could exert most definite action.

The first is the promotion of interest in leprosy in a number of endemic countries. In more practical terms, what is suggested is the creation or support of national or regional leprosy associations which should serve to stimulate leprosy activities locally in endemic countries. These associations can take many forms. They might be scientific bodies, unions of patients, or welfare organizations. Whatever their specific purpose, they have, however, a common function, i.e., to promote interest in leprosy and to facilitate activities at various levels. They can have a determining role in shaking bureaucratic inertia and stirring public interest. Such associations do exist and are quite active in some countries. The International Leprosy Association should reinforce its links with such associations. Their creation should also be encouraged wherever the need is felt. The *JOURNAL* could serve as a useful tool to disseminate relevant information in this respect.

The second area involves an admission of failure by all of us. In very many countries where leprosy is highly prevalent, there is at times a relative or at times total disinterest by the medical profession in leprosy. I shall not dwell on the consequences, which include poor care, denied access of patients to health facilities, collapse of control activities due to lack of appropriate management or supervisory staff, excessive reliance on expatriate physicians, and low productivity of research. One reason at least for this situation is that most universities do not give leprosy its due share in the curriculum. In many countries where leprosy is endemic it is not taught as it should be, as much as it should be, and to whom it should be. How can we effectively control leprosy, provide better care for patients, or apply the results of research if physicians are turning away from the disease? The same remark applies to scientists. Young researchers at the moment are not attracted to leprosy. It is not considered a fashionable field. Of course, we all agree that this is a considerable mistake. Leprosy is a model disease where many unknown

questions are challenging, be it in immunology, in microbiology, in epidemiology, or in other branches of research. Serious consideration should be given to these points by members of the International Leprosy Association because to some extent, one way or another, many of us are part of academia. We should ask ourselves if we have done what we ought to do to promote the teaching of leprosy in universities and to stimulate young physicians and scientists to become interested in the disease.

National or regional leprosy associations and appropriate teaching of leprosy in the universities are two points which need to be discussed. The columns of the JOURNAL are open for any suggestions, reporting of

actual experiences, news, and comments. More exchange regarding these points is sought.

Fifty years ago a group of leprologists founded the International Leprosy Association, creating the conditions for great advances in leprosy. Considerable successes have been obtained. Old challenges have been met. New challenges have arisen. Let us hope that these new challenges will be met with the same determination our predecessors have shown. If so, 50 years from now leprosy will be, if not eradicated, at least widely controlled throughout the world.

—Michel F. Lechat