

WHAT SHOULD ILA BE? - A PERSONAL VIEW

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ILA President

Introduction

Although I am its President for a second term, I must confess that I am still incapable of defining the current ILA accurately. My first contact with it was in 1958, when the 7th International Congress of Leprology, which was the title of our Congresses in those days, was held in Tokyo. I was appointed as a liaison between ILA, (represented by Dr. H. W. Wade, its President, Dr. E. Muir, its Secretary and Dr. J. Ross Inness, its Secretary-Designate and the *de facto* Secretary of the Congress) and the Japanese Organizing Committee. In fact, it was those three doctors who, immediately after the Congress, persuaded me to go to medical school at the age of over 30, saying that I should have a medical qualification, especially if I wanted to work overseas, even if my main interest was in the social aspects of leprosy. I am forever grateful to those three eminent doctors in leprosy, plus Dr. S. G. Browne, who became my mentor after the untimely death of Dr. Ross Inness, for their advice and subsequent support in making me what I am today. However, somehow it never occurred to me to join ILA, even after starting my leprosy work by joining The Leprosy Mission in 1970. I thought rather vaguely that ILA consists of people whose interests are somewhat different from mine, which was the rather down-to-earth daily care of the patients as a clinician in a developing country, while those of ILA members, judging them mainly from IJL, were rather at a stratospheric height of leprosy study.

I had to join ILA when I was asked to be the Secretary of the Association by Dr. Wayne Meyers, my predecessor as the ILA President. The reason for my acceptance of that post was a sense of indebtedness to those four outstanding ILA Officers, and serving a term as Secretary was meant to be a symbolic repayment. It is amazing how things can develop unexpectedly), and I ended up as the President at the Orlando Congress. To be honest, I have never been really comfortable either as the Secretary or the President over the last 10 years because I was never sure of what ILA is, at the same time becoming more and more aware of the probable discrepancies between what I think it has been and what I believe it could and should be. The acceptance of my second term as ILA President, due to strong external pressure from an unexpected corner only a few months before the Congress when I was having discussions with a potential successor of my own choice,

was of course ultimately my own choice, and the reason then was my very personal sense of duty to a necessary reform of the Association as I see it.

As many of you have witnessed in Beijing, some with delight but others with horror, the format of the 15th Congress had been changed quite drastically. I did that because I was told by my fellow ILA Officers that it is a President's prerogative to decide what sort of Congress we should have. Although ILA is mainly responsible for organizing the Congress, it has two co-sponsors in WHO and ILEP with their own firm ideas. Besides, two third or more of the participants in recent Congresses have been non-ILA members. Thus without too much fear, I could organize the Beijing Congress to suit what I considered to be the needs of the prospective participants. I am now getting returns off the questionnaires which were sent out to all the participants, and they clearly show that the majority of them definitely liked the new format but, equally, the returns indicate that many ILA members, especially those in research in the West, definitely did not like it. There is no surprise in that at all, although it is a difficult and, at present, almost insoluble problem to reconcile the needs of two diverse groups in a single one-week meeting. Perhaps we should run two Congresses concurrently, one smaller and scientific and the other much larger and nonscientific (meaning control and social aspects), with only the opening and closing sessions together.

However, trying to change the character of ILA itself is quite a different matter altogether. It needs the consent of a majority of the current members, and the President has only a single vote to cast, like any other member. There are a number of current members, some within the Council, who favor some changes, changes even more radical than mine. They are the more vociferous members of ILA, willing to come to the General Meeting of Members on the final day of the Congress and openly demand some changes. But if my guess is correct, they are still a minority within the Association, leaving a silent majority who are either satisfied with the current ILA and thus wishing no change, or perhaps do not care much one way or the other, provided the "status quo" is maintained.

Fully realizing this state of affairs, I am starting a series of events which I have already described in the Foreword of this issue. If all goes well according to my plan, it will end in a postal referendum in the summer of the year 2000, result of which will be considered and appropriate actions, if any, taken at the full Council meeting, which I am calling on the occasion of the ILA Asian Congress in India in October/November 2000. If at all, I shall propose changes in technical details of the Bylaws only, while leaving changes in the Constitution, such as objectives and memberships, to the General Meeting of Members at the time of the 16th International Leprosy Congress to be held probably in the year 2002 rather than 2003 somewhere

in Brazil.

Why changes now?

At this point, it is necessary to consider the reasons for changes now. Apart from the reasons to be explained in the next section, which one might call ideological, there are more mundane but rather urgent reasons which are primarily financial.

The size of our membership is slowly but steadily contracting, mainly due to loss of our scientific colleagues for very understandable reasons. They seem to find less interests and/or opportunities in engaging in leprosy research. This trend, which is certainly regrettable but beyond our control, is likely to continue. Thus, our income from the membership fees of self-financing individuals is steadily being reduced. There seems to be ample opportunities for a large increase in membership from leprosy workers, both medical and social, in endemic countries whose activities are likely to continue. But for them, the current membership fee tied to the IJL subscription is simply prohibitive. It is suggested that US\$10-US\$20 annually would be an affordable level for them. Thus, an increase in membership does not necessarily help financially.

Reduced membership together with the increasing costs of producing and mailing IJL are threatening our ability to keep producing the IJL as it exists today. The publication of a scientific journal on leprosy is the only activity specifically assigned to our Association by the ILA Constitution. Its publication nowadays is almost entirely at the mercy of the members of ILEP, and there is a constant questioning of the wisdom for them to keep supporting two international leprosy journals of similar contents and quality in English, thus increasing financial support from that source seems totally out of the question.

Each of the above, by itself, does not allow us the luxury of "no action" until the next Congress. Added to these, the reasons to be stated in the following pages make it imperative for us to take some action soon. We cannot afford the "status quo" which ILA seems to have enjoyed, or suffered depending on one's view, for far too long. I am not expecting everyone to agree with my reasoning for changes on "ideological" grounds, but I hope everyone will realize that without some changes financial reasons alone could doom the future of our Association.

I am fully aware that some members of the Association, including a few on the Council, are of the opinion that if ILA is doomed to die, it is best to let it do so without much disturbance now. Others say that if ILA is not meeting the needs of the current leprosy world, it is better to create another association specifically able to meet such needs. I happen to disagree very strongly with such ideas. I firmly believe that both the name and the

substance of ILA are worth preserving because, at least in my view, the founding fathers of our Association made sure, in our Constitution and Bylaws, of our continued existence and expected contributions to global leprosy work. Creation of such an organization was seriously debated and a special committee was created at the time of the first Congress in Berlin in 1897, but it took more than 30 years to actually establish ILA. Surely we should not abandon such an organization so readily, not while I am its President for sure.

Now let me come to my personal views on "What is ILA?" and "What ILA should be."

What is ILA?

As I have said already, I am not capable of defining either the nature or the *raison d'être* of the current ILA accurately. It is said that it has to be an association of "professionals," to which I am inclined to agree, although without being able to define "professionals" exactly. It is also said that it is an association of "scientists" and "academics." Here I tend to disagree, although I am equally unclear as to what those two terms mean, while recognizing that many of the current members seem to belong to these two categories.

The existing ILA Constitution does not seem to stress that the Association must be "scientific" or "academic", although it may vaguely imply that it should be an association of "professionals."

It states that the members are: 1. Persons holding recognized medical or scientific degrees; 2. or other professional qualifications; 3. or persons who are, or have been, actively connected with leprosy work.

The underlining is mine, and a very loose and all inclusive membership it is indeed. If you take these criteria literally, anyone with a medical, scientific or some other qualification could be a member, even if not engaged in leprosy work at all. At the same time, anyone associated with leprosy work, currently or in the past, could be a member without any qualification.

Why such loose criteria? I suppose in early 1930s, the number of people genuinely interested in leprosy was so few that almost anyone wishing to join the newly established Association was welcome. Is the current situation that much different? I wonder.

As to its objectives (objects) the ILA Constitution states: 1. To encourage collaboration between persons of all nationalities concerned in leprosy work. 2. To facilitate the dissemination of knowledge of leprosy and its control. 3. To help in any other practicable manner the antileprosy campaign throughout the world. 4. To publish a scientific journal of leprosy. 5. To cooperate with any other institution or organization concerned with

leprosy.

Again, very broad objectives indeed, except for No. 4 which is very specific. Almost any activity of leprosy, including its control and campaign, from finding individual patients to rehabilitation of those affected by the disease, as well as more scientific activities to find new tools required for such activities, or elucidating the basic structures of *Mycobacterium leprae* and their functions could all be considered as its legitimate concern.

From the existing ILA Constitution, if it had not been drastically revised meantime, which I rather doubt, it is obvious that the founders of the Association felt a need to establish a network of people working in leprosy in order to improve leprosy control and strengthen the global antileprosy campaign, thus helping individual patients under their care. Perhaps they could not afford to be too restrictive in terms of membership qualifications or objectives of their activities because there were only a precious few who, in their eyes, could be members of the new association they were creating.

Is the current ILA doing those above-mentioned jobs well? In my personal view, the answer must be a negative, almost totally negative I am afraid. Certainly, quite a large number of individual members are now contributing greatly to promote some of the activities mentioned above, working with WHO, ILEP, other international or national NGOs, and technical or academic institutions. However, the Association itself, is not doing anything. Evidently many members think that the Association itself has no business taking any action at all, but that view seems to be in conflict with the objectives stated in its Constitution.

There are two types of associations. One is inward looking; its only reason for existence is to meet the needs or cater to the tastes of its members, whoever they may be. The other is outward oriented, and it exists basically to do something collectively, primarily for the benefit of others, although by so doing the members are likely to derive some satisfaction for themselves. I feel somewhat uneasy with ILA because to me ILA seems more of the former than the latter. For that reason, my original intention was to leave ILA once my term as President was over at the Beijing Congress. But, as I explained earlier, I felt I have to continue, not so much for the sake of ILA as such but for the sake of leprosy in a broader context. Once I decided to accept a second term, it became a matter of conscience to try to be an active President, and that meant I must try to reform ILA, although the eventual outcome of my effort rests squarely on the majority opinion of the current members and, thus, is mostly out of my control.

What ILA should be

In the past, there was no demand on ILA to take a strong stand concerning the global leprosy situation or show strong leadership in the

global leprosy program, although at some Congresses it produced some timely and useful recommendations, suggesting ways with which to improve or strengthen existing leprosy work.

Clearly, the founding members felt a need for closer communication among the few leprosy specialists in the early 1930, practically all of them clinicians dealing daily with leprosy patients. Perhaps they felt their isolation, both in physical/geographical terms as well as in a professional sense, to be a great advantage to their work. Therefore, the exchange of ideas and experiences among the members was obviously the felt need among them, and perhaps a newly born sense of fraternity among them was enough in the beginning. The absence of technologies which could dramatically change the global picture of leprosy, even with the discovery of sulfone therapy in the early 1940s, was enough to keep ILA rather static over the next 50 years.

The appearance of multidrug therapy (MDT) has changed the global scene completely. Unlike Promin and dapsone, MDT has proved to be really effective in controlling leprosy in the world under field conditions, at least as an infectious disease if not as a deformity- and disability-producing disease. A need for strong leadership to direct such a global movement became apparent which, by the nature of activities required, had to be carried out by the field workers of leprosy-endemic countries in the world. The logical choice of such a leadership fell on the Leprosy Unit of WHO and, to their great credit, they have performed their function very well, with the "elimination of leprosy as a public health problem by the year 2000" nearing its end. Whatever its detractors may say, there is no question that by reducing the global caseload by 85% or more, the global leprosy scene in the year 2000 will be quite different, quantitatively as well as qualitatively, from what it was in the early 1980s when MDT was first introduced.

But the very success of this program itself, plus the rather unexpected fundamental restructuring of WHO, means that WHO is unlikely to be able to exercise the kind of leadership required for future global leprosy activities after the year 2000, which will be vastly more diverse and complex, requiring many different tools and technologies and involving a variety of workers, unlike the relatively simple and uniform MDT implementation up to now.

There is another strong group, as a potential leader, called the International Federation of Anti-Leprosy Associations (ILEP), formed by 20 or so of the international NGOs, with combined financial resources of around US\$70-US\$80 million annually. They have been the major supporters of the global implementation of MDT so far, and there is good reason for them to become even more important supporters of the global leprosy program soon, in which social aspects must have an increasingly larger share. But there are

two reasons, one inherent and thus unavoidable and the other structural and thus possibly alterable, which make them not quite suitable as a world leader, at least at present. One is the fact that they are basically donor agencies, and two donor agencies, the International Monetary Fund (IMF) and the World Bank, are increasingly being criticized nowadays for their behavior. Donor agencies have a tendency to dictate the use of the funds they provide in a way not necessarily in the best interests of the recipients. Another is structural, and as a federation it is difficult to have united action among its members.

If both WHO and ILEP are unsuited to be the global leader, then who else? As far as I can see, there is no one at present and the only possible candidate is ILA, not as it exists now but as a reformed ILA. Of course some people, including many current members of ILA, could question the need for global leadership after the year 2000. But I, for one, happen to believe in our mission to work toward our final goal of "A World Without Leprosy," and for that goal to be reached within our foreseeable future, say not later than the year 2050, then globally a concerted effort by all concerned is required, which naturally calls for effective leadership.

I use the term "effective" rather than "strong" because the leadership of ILA is likely to be by persuasion only. ILA is unlikely to have a fund of its own sufficient to undertake any activities by itself. The only way it can function as a leader, in my current view, is to form a kind of "think tank," or several of them, primarily working by correspondence (which modern technology is making ever easier and speedier on a global scale) and not requiring a large sum of money. ILA also will have to be able to market those ideas which come out of our "think tanks" if they are to be accepted by those who are capable of taking action, such as member organizations of ILEP, other national or international NGOs, national health authorities, and even WHO, the World Bank and other international agencies that can take large-scale action by themselves or can prompt such action to be taken by others.

Of course, one great advantage of ILA which it already possesses is that many individuals who are likely to be responsible for taking action in leprosy are those likely to be the current and future members of our Association, although at the moment not enough people in the endemic countries are members nor are the experts in the social aspects of leprosy work.

Therefore, the ILA of the future, in my personal view, must be an:

1. Association which is both sensitive to the needs and capable of understanding what are the existing problems which prevent those needs from being met.
2. Association capable of coming up with ideas and even actual plans to solve those problems effectively and efficiently, and skilled in

"marketing" those ideas so that someone capable of taking action will accept those ideas. 3. Association of strong and clear advocacy for further leprosy work in all aspects in order to reach ever closer to "A World Without Leprosy."

In other words, I want to make ILA a pro-active Association relevant to the global needs of leprosy of the times, and responsible in realizing our common goal, thus bringing satisfaction to individual members who, in turn, should feel proud of their membership in the Association.

Am I too ambitious? I do not think so. I believe we could and should try to create such an Association, in the name of ILA.