

# HANSENOLOGIA INTERNATIONALIS

(Hansen. Int.)

## The story of two appeals to banish the term "lepra" and the harsh lesson to Latin America

EDITORIAL

Dr. Stanley G. Browne invited the undersigned to report on the stigma of "leprosy" on two occasions :

1. As Editor of "Leprosy Review", to its readers (1972).
2. As Secretary-Treasurer of the International Leprosy Association, to its Council, at the X International Leprosy Congress (Bergen, 1973).

On both occasions the invitations were promptly accepted and the arguments against the word "leprosy" well understood — but the appeals to banish it were rejected. The story is very illuminating and should deserve the closest attention from Latin-American governments.

### ARGUMENTS ACCEPTED/ APPEALS REJECTED

1. In the article : "The Serious Latin-American Problems Caused by the Complex "Leprosy, The Word, the Disease", and an Appeal for World Cooperation" (3), all the moral, social and prophylactical damage caused to Latin America, by the opprobrious word "lepra" were documented and all the usual arguments to conserve it were

rebutted. It concluded with an appeal to the English and French-speaking countries — who have inherited. the words "leprosy" and "lèpre", but *not* the disease — to banish those words on behalf of the Latin American nations in development — who have had the misfortune of inheriting *both* the word "lepra" *and* the disease.

In a subsequent issue of the magazine, the arguments for a terminological change were practically accepted, but the appeal was criticized and rejected on two grounds:

a) On the financial grounds — an Officer of the British Leprosy Relief Association ("L E P R A"), which owns said magazine, writes (6) that "one approaches such a paper with profound humility, and with acknowledgement that the deeply felt plea is for help with a local problem". *"This in turn invites a desire to agree with the recommendations"*. (emphasis added)

That most valuable cooperation, however, was denied to us. Two lines from the abstract summarize his viewpoint : "Despite arguments put forward in Leprosy Review (1972) 43, 69-105, (\*) there is a case for retaining

(\*) The pages of this reference include an editorial in the same issue of "Leprosy Review" (5), non-antagonistic to a terminological change, wherein the Editor asks: "The word 'leper' is officially banned; should not 'leprosy' go the same way?"

the substance of current terminology related to leprosy, *particularly because of its value to fund raising.* (emphasis added)

b) On the grounds of "indifference" — the article was also castigated in the same issue. The Editor of the "International Journal of Leprosy", writing unofficially as a member of the "Leprosy Atelier", Honolulu, Hawaii (4) admits that the arguments for the Brazilian terminological changes "are Perhaps well taken". This is a welcome progress, considering the well known antagonistic past of the Editor.

The appeal, however, was rejected: "Indeed, this is one reason. that *one wonders at the effort to change world-wide practice* (the word "leprosy") *"in order to achieve a social and cultural change in Brazil"*. (emphasis added)

(To be exact, it is not a "world-wide" practice, but only a word in the Anglo-Romance languages, and it is not Brazil alone, according to the title and text of the appeal, but all of Latin-America and all other countries where those languages are spoken.)

2. The verbal report to the Council of the I.L.A. had an even sorer outcome. In spite of being upheld by 117 signatories from 15 countries the appeal "to study the possibility of a new terminology" was flatly rejected. True, *the Council recognized the problems caused by the word "leprosy" in some countries, who were declared "free to choose any other name for their convenience"*. But even this ineffective and confusion-calling consolation prize disintegrated somewhere. *It was never printed in the official "Journal", although that recognition had been the result of two meetings of the Council.* Except for the Councillors present at the second meeting, no other member could have known about that new I.L.A.

policy if a report to the "Star" (1) and, three years later, our periodicals had not belatedly published• the news (2).

## HARSH LESSON TO LATIN AMERICA

Latin-Americans who are still in doubt about the moral, social and prophylactical malignancy of the term "lepra", are hereby again advised that *such malignancy has been officially recognized by the Council of the I.L.A., as well as, semi-officially, by the Editor of the "International Journal of Leprosy" and by a representative Officer of "LEPRA", the owner of "Leprosy Review"*.

Unfortunately, it should also be recognized that such malignancy, in all likelihood, will go on damaging for many and many years.

Most English and French-speaking authors are presumably not at the moment going to change their practices "to achieve a social and cultural change in Brazil" — or in any other developing endemic Latin-American country. This is not based only on the viewpoint of the Journal's Editor, who reflects the opinion of a majority in the United States and in the United Kingdom, but also on the known fact that 46 years after the condemnation of the word "leper" by the Conference of Manila (1931), ratified by successive Congresses of the I . L . A., its "lépreux" equivalent still abounds ominously in the French medical literature. Things would certainly be different if "leprosy" — the disease and the stigma — abounded in France, Great Britain, the U.S . and Canada, countries whose social and cultural problems would not be so flatly ignored.

Presumably, the British "LEPRA" and the "Leprosy Review" are not delib-

erately going to suffer financial losses to help Latin-America with a new, educational and non-stigmatizing terminology. The I.L.A. had never accepted changing its own name in the past and does not seem willing to do so now. The World Health Organization seems to follow the I.L.A.'s policies on this subject, at least up to date.

### CROSS ARMS OR FIGHT?

The obstacles are practically unsurmountable and might discourage many. Others might think it more honorable to go on fighting and die an honorable death. For these there are a few weapons left.

Latin-American countries could, for instance, officially adopt the term "Hanseniasis", as has been done in Brazil, or the equivalent of "Hansen's disease", recently adopted by the U.S. Public Health Service, or else "Hansenosis", recommended to the Peruvian Government by the Seminar "Hugo Peace", at Pucallpa, Peru, 1974.

The other weapon is *Union*. *United* we could plan a common strategy to avoid or minimize the problems caused by the imported "leprostigma" which will continue invading our countries, demoralizing our citizens and upsetting our educational and prophylactical programs.

*United*, we could decide unilaterally to substitute a *Mycobacterium hansenii* (Feldman, U.S., 1953) for the opprobrious official *Mycobacterium leprae*.

*United*, we would be more forceful in calling the attention of both the W.H.O. and the I.L.A. to our grave socio-linguistic-medical problems, and perhaps receive the benefit of their valuable cooperation. *United*, we could appeal to the conscience of our English

and French-speaking colleagues, eventually convincing some, at least, that their collaboration in erasing a stigma — and a disease — from our underprivileged countries is an ample compensation for the relatively small annoyance of substituting "Hansen's Disease", "Hanseniasis", or "Hansenosis" for the dread and terrorizing "leprosy/lèpre". If "sexually transmissible" is now the official substitute for the "venereal" diseases, there is no reason why "leprosy" should not be changed as well.

*United* we could dare to convince voluntary agencies that there is no charity in giving to a few at the cost of the suffering of many; and even that there is much more charity in wiping that black spot out of a civilized world — the pejorative "leprosy" — than in providing food, shelter and medical aid to a small part of those who really need them.

### WHERE AND WHEN?

A new association of Latin-American hansenologists or an informal group within the frame of the I.L.A. could be considered. The latter suggestion would have the advantage of beginning to work at the International Leprosy Congress, Mexico, 1978 — if we receive names and comments in the shortest possible time.

However, we believe that the ideal forum is the College of Hansenology of the Endemic Countries, in organization. One of its important objectives is the study of all social factors which are creating problems in endemic areas, blocking education and the control of the disease. There we would meet non-Christian countries who also have problems with their local pejoratives. We may also meet colleagues from non-

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-endemic developed areas willing to give us a hand.

Incidentally, it may be a surprise to some, that we have among the Founders of the College quite a few American and

French workers already cooperating to "achieve a social and cultural change" in our underprivileged, endemic and developing countries.

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