

OUR FIGHT AGAINST LEPROSTIGMA WILL BE LIMITED TO BRAZIL

EDITORIAL

"Hanseniasis" is the medical term introduced in the State of S. Paulo, Brazil (1967) to initiate the liberation of a common physical disease caused by *Myco. hansenii*¹ from the dinosaur-like size and weight of the terror, ignorance, superstition, stigma and sensationalism perpetually yoked to the pernicious, degrading and loathsome pejorative "leprosy". The new medical name rapidly spread to other States, was adopted by the Brazilian Dermatological Nomenclature (1970), by the federal administration (1975), by the edition in Portuguese of the International Classification of Diseases of the World Health Organization (1978) and by many general and medical dictionaries and periodicals. Although liberation is only at the start, its first educational, psychological, social and prophylactic advantages can already be seen in this country.

International indifference

Our attempts to "export" our new name and its incipient benefits failed. With the exception of Bolivia, Latin American countries — the world's most numerous and worst victims of the complex "leprosy, the disease, the

shameful pejorative" — ignored or attacked us. To some, our professors, public health authorities and participants of national congresses were no more than a few "kindhearted naïves²"; to others, on the contrary, we were the devilish spearhead of "Brazilian imperialism", trying to engulf all of South America (verbal comment, medical congress of a near country).

With shipwreck mates treating us this way, nothing positive should be expected from the vast majority of non-victims of the "complex". Why should African and eastern endemic countries be unhappy about an Anglo-Romance defaming pejorative that does not belong to their languages and dialects? On the other hand, why should English and French speaking non-endemic North - American and European countries worry about a degrading pejorative of their languages that does not harm their fortunate citizens? The situation is clearly synthesized by a former American editor of the International Journal of Leprosy: "Indeed, this is one reason that one wonders at the effort to change worldwide practice in order to achieve a social and cultural change in Brazil"³.

(1) The non-stigmatizing term *Mycobacterium hansenii* was adopted by "Hansenologia Internationalis" after the favorable results of an inquiry in Brazil (Hansen. Int., 6(1):71, 1981) It was accepted by the I Congress of Hansenology of the Endemic Countries and III Brazilian Congress of Hansenology (Rio de Janeiro, 1980) as synonym for *Mycobacterium leprae*.

(2) Int. J. Lepr., 47(2, suppl.): 259, 1979.

(3) Lepr. Rev., 44:94,73, 1973.

This worldwide indifference towards that grave Latin American linguistic-socio-medical problem is reflected by the fact that the International Leprosy Association has never agreed to change that defiling and noxious pejorative, in spite of having recommended to use the word "leprosy" with caution, "since it tends to have a socio-historical, in addition to a medical connotation" (11th International Leprosy Congress, Mexico, 1978). The World Health Organization has never given enough consideration to a vexing question which is being fiercely debated for almost a half-century since the American patients' magazine "The Star" opened fire against a "treacherous, dirty, demoralizing and objectionable name, distressing to patients and their families, terrifying and inflammatory to the public", and has never replied to our repeated appeals to "confirm or negate" successive Brazilian, Argentine and American inquiries which have concluded that the pejorative "leprosy" is a "disintegrator of the patient's personality", a "prejudice-loaded, stigmatizing and counter-educational term", a "continued psychic pain and trauma" "the most negative of all medical terms".

Leprostigma is money

Aggravating our unfortunate situation, other formidable roadblocks showed up — the powerful and influential charities of the western world, that need to open the purses of reluctant contributors. "To change the name of the disease long known as leprosy would tend to shut off the sources of good will leading to financial aid", warns a renowned English author⁴ "Despite arguments put forward in Leprosy Review fours, which were accepted "with profound

humility"⁵) the word "leprosy" should be retained "particularly because of its value for fund-raising", states a member of the English "LEPRA"⁶.

Summing up, "leprosy" is money, "hanseniasis" it not. We should perish so that some charities do not perish.

We change our goals

It is about time to consider that we will never overcome such worldwide indifference and such tremendous opposition. With a clear conscience that we did our best to save the patients of the western world from the infamy of "leprosy" and to contribute for the prevention of the disease in our region, we stop now a useless international fight and concentrate our efforts in Brazil, amplifying and reinforcing our still incipient good results.

Before this century is over, Brazilian patients and their families should be cured from the psycho-social disease called "leprosy", which is much more widespread and disgraceful than the somatic disease "hanseniasis" ; they must leave their hiding-places and must massively look for doctors and health centers — for their own sake and for the sake of prevention. The internationally recommended "case finding", that is, looking for needles in haystacks, and the technically impossible education and rehabilitation with a counter-educational and counter-rehabilitative "label of primary force" shall be in this country only remembrances of an infamous and backward past. *These are our new goals.*

We regret...

We regret that the world which throughout the centuries has discarded the ritually defiling "leprosy" of the

(4) Int. J. Lepr., 38: 207, 1970.

(5) Lepr. Rev. 43: 96, 1972.

(6) Lepr. Rev. 44: 70, 1973.

Bible, replacing them with medical names like "vitiligo", "psoriasis", "tinea" etc., forgot us and insists that our hanseniasis patients bear — *alone* — the tremendous weight of "Biblical leprosy", which, as everybody knows, has nothing in common with their disease.

We regret that the medical world, that is continuously changing names of diseases and syndromes, and that a few years ago rapidly substituted the term "sexually transmissible" to erase malodorous overtones of the "venereal" diseases, does not pay attention to the much more malodorous "leprosy" of our forgotten country.

We regret that the voluntary agencies of the Western World can not find ways of practicing their charity without contributing to the shame and despair of our patients and their families, to their hiding and consequently to the aggravation of their disease and of our endemic.

We intensively regret that some of those agencies and many doctors still use the ultra-stigmatizing words "lepers", "lèpreux" and "lebbrosi", condemned by the Leonard Wood Memorial Conference (Manila, 1931) and by more recent Congresses of the International Leprosy Association.

... *thank* ...

We thank all persons in over 50 countries, particularly in the United States, Argentina, Peru, Japan, India and the United Kingdom who, diverging from the overwhelming majority, have given their precious support to our 17 year old campaign.

We thank the Public Health Services of the United States, Bolivia, Jamaica, Trinidad-Tobago and Guyana ; the Ministry of Social Affairs of Portugal and the Government of Italy for having adopted the term "Hansen's

disease", thereby acknowledging the opprobrious and dangerous overtones of the pejorative "leprosy".

We thank the translators of recent English and Spanish Bibles for having expelled the odious and ostracizing pejorative "leprosy", replacing it with vague names like "skin diseases", "infections", "molds", etc. — despite the fact that the Bible is not responsible for the medical misuse of the pejorative "leprosy", the ritually defiling Hebrew "Tsara-ath".

... *and invite*

We invite all Brazilian workers in the fields of medicine and allied sciences, psychology, sociology and education to *give* us their necessary support or to reinforce their previous fruitful cooperation.

We invite authors of general and medical dictionaries, journalists, writers and everybody in the communication area to cooperate with us by clearly separating "hanseniasis", the physical disease, from "leprosy", the ostracizing stigma, a synonym for "filth", "terror" and "loathsomeness".

We invite the Brazilian voluntary agencies that have already adopted the name "hanseniasis", to apply at least part of their commendable activities on this new educational and psycho-social program.

And we invite all people of good will to found philanthropic centers in each State or Territory of Brazil with the objective of integrating hanseniasis patients into our society, facilitating their early diagnosis and treatment and easing the preventive activities of our public health services.

We are almost alone. We must redouble our efforts if we really wish to start ridding Brazil from leprostigma and hanseniasis.

A. ROTBERG