

WE DISAPPROVE OF FUND-RAISING BASED ON STIGMATIZATION

EDITORIAL

In an article published in "Leprosy Review" * one of the officers of the British Leprosy Relief Association ("LEPRA") explains that in order to raise funds in the United Kingdom, successfully competing against 77.000 local charities, and to go beyond the barrier represented by the nationalistic feelings of the British public ("Charity begins at home"), his "overseas" charity "must involve the potential donor in thought and in feeling of obligation... and the evocation of a reaction to the word "leprosy is an essential factor in stating the case". "Because of all the factors which frustrate the efforts of field workers, the word leprosy invites curiosity and attention and provides for a strategy in gaining support". "This seems a legitimate and harmless process". "In a similar way, pictorial representation of leprosy sufferers provides immediate information about the nature of the disease, but stressing the unaesthetic aspects of it, seems calculated to reinforce stigma".

In the summary, it is emphasized that "there is a case for retaining the substance of current terminology related to leprosy particularly because of its value to fund-raising".

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International bodies and Congresses, reflecting world consensus, have repeatedly condemned sensationalism through pictures of patients, and many

authors and inquiries have stressed the even worse influence of the word "leprosy" itself.

The author of the article is well aware of the sensationalism and stigma attached to the instruments used to motivate the British public. The Brazilian name-changing appeal is "approached with profound humility and with acknowledgement that the deeply felt plea is for help with a local problem".

However, the idea of fund-raising predominates in the article, in spite of the social harm it causes. "Fundraisers, are, then, faced with a considerable dilemma. Do their efforts to provide funds for treatment and research perform a disservice to their medical colleagues, prolonging traditions...?" "It is a dilemma which cannot be resolved if the answer is affirmative, for a loss of income must affect the anti-leprosy work adversely". "We take it for granted that the more money we can provide, the greater will be the momentum of treatment and research programmes..." "Even against the background of implicit disapproval, we have to continue to rely on the dynamics of an appeal..."

Therefore, facing the dilemma, the choice is made: *fund-raising first, even with perpetuation of stigma and prolongation of traditions, and even against the background of implicit disapproval by the author's medical colleagues.*

(*) Stringer, T. A. Leprosy and "a disease called leprosy". **Lepr. Rev.**, 44:70-74. 1973.

We declare our choice: no money, if to raise it the infamous traditions of "leprosy" must be prolonged. We do disapprove all fund-raising activities based on perpetuation of stigma, ignorance and superstitions.

We consider that the *limited* amount of charity and research provided by the funds do not at all compensate for the *unlimited damage* to the morals and the social status of many millions of patients and families — who hide themselves for fear and shame, and in vast majority, do not seek the treatment provided by governments (or, *to a much minor degree, by charities*), and do not benefit, therefore, from any scientific advances.

We do not agree that this is a "legitimate and harmless process". Pictorial representation of the unaesthetic aspects may be so, as in "LEPRA" 's fund-raising campaigns it is restricted to Britain, were, fortunately, the "psycho-social-somatic" phenomenon of "leprosy" does not occur — although we are of the opinion that the British public also deserves the benefit of more sober and equilibrated notions about the disease. But the defense of *the shameful and ostracizing pejorative "leprosy" through an internationally circulated and influential magazine is illegitimate and tremendously harmful for all endemic regions where that pejorative or its translations are used.*

We are grateful to the "LEPRA" 's officer who, with his long and wide experience in the field, *gave* professional support to all those who accuse the terrorizing pejorative "leprosy" of being at least as emotion-loaded and nerve-shattering as the unaesthetic pictorial representation of patients — a

fact still ignored by the vast majority of his medical colleagues.

However, we hope that in the civilized era we live in, the "LEPRA" and other voluntary agencies will find ways of continuing their highly commendable work without contributing through horrifying pictures and words, to the permanence of stigma and of all the social and preventive problems it causes.

NOTE — This editorial is reprinted from "Hanseniasis, Abstracts and News" (7(1/2):6, 1976) and from "The Disease Hanseniasis" (1 (2) :173, 1977) in order to confirm the standing of "Hansenologia Internationalis" in the difficult fight against "stigmatizing charity", that is, the fund-raising activities by sensationalistic and stigmatizing words and pictures, which perpetuate the social problems of patients and their families, drive them into concealment, aggravate the disease and the endemic.

We beg the World Health Organization, the International Leprosy Association and the College of Hansenology of the Endemic Countries to program studies to assess : 1) the moral damages inflicted on patients and on their families by stigmatizing fund-raising activities and 2) the preventive problems caused by the same.

We beg our readers to make copies of this editorial and send them to local Ministries of Health or Public Health Services, as well as to charities which continue raising funds with the help of horrifying pictures and/or degrading terminology.

Thank you.