

Letter to the Editor

A correction would seem in order for a misrepresentation appearing on page 104, point (8), in the presentation by A. Rotberg, "Leprosy, the Word, the Disease," [*Lepr. Rev.* (1972) 43, 96-105].

In Hawaii from 1947 to 1969, the term "Hansen's Disease" was the legal term for leprosy. Cooperation in the use of this term during that period seems to have been as good as could reasonably be expected. Certainly the leprosy service and those connected with it made a distinct practice of using the term "Hansen's Disease" and the habit still prevails to a remarkable extent.

Dr Rotberg's sweeping contention that "there is not the slightest resemblance between the social, racial, cultural, religious and epidemiological conditions of Brazil and the State" is a bit exaggerated. However, his point that the situation in Brazil is different in many respects is perhaps well taken. Indeed, this is one reason that one wonders at the effort to change world-wide practice in order to achieve a social and cultural change in Brazil.

The official return to the use of the term "leprosy" in Hawaii was not in any way due to "the existence of a determined opposition by at least one influential author" (Skinsnes, 1966), and Dr Rotberg clearly did not make a reasonable "search of the literature" on this point, as he implies. The pamphlet referred to was sent to him by me, though not requested. In the scores of columns written in the local papers about leprosy since I became resident in Hawaii, there is not a word of "determined opposition" or even casual comment by me on the question of disease terminology. There is no writing by me in any Hawaiian publication on this matter.

The changes respecting the control of leprosy in Hawaii, including the use of the word "leprosy" resulted from long hearings, careful consideration, full discussion and deliberate recommendations made by an appointed "blue-ribbon" Citizens Committee composed, with one exception, of long-time residents of Hawaii, including leprosy patients. I appeared once before this committee as an "expert witness" regarding liberalization of rules of leprosy control and treatment and assuredly did not make any "determined" or other sort of plea regarding terminology. Nor was I then a member of that committee, having become a resident of this state only the year before the committee began its work, i.e. in August, 1967. Altogether 12 expert witnesses or committee members were available. My pamphlet, to which Dr Rotberg gives reference, had at that time no influential circulation in Hawaii that I am aware of, though it was circulated to the committee. The committee concluded, with respect to the matter of terminology: "Finally, the substitution of the term 'Hansen's Disease' in place of the word 'leprosy' only intensifies the problem it is supposed to eliminate—a centuries-old fear of the disease. The solution to this problem is proper education of the medical and lay community, not the substitution of an allegedly innocuous euphemistic term. If 'leprosy' is such a bad word that it should not be used, it automatically follows that the disease is unspeakably dread." The opinion was

that the 22 years' experience in changing the disease name had done no significant good. No one crusaded for the change.

Dr Rotberg would have been more equitable had he made reference to my three publications relating to the problem of leprosy opprobrium which appeared in *Leprosy Review* (1964, 35, 21-35, 106-122, 175-181), on which studies the pamphlet he refers to were based. The pamphlet, incidentally, carries these references, and reprints were sent to him together with the pamphlet. The pamphlet is not likely to be available to many of your readers and the milieu of Dr Rotberg's presentation leaves the impression that that writing is unsympathetic to the suffering brought by leprosy and is a "determined opposition" to the forces of good. The study referred to, on the contrary, was a long and extensively researched attempt to reach a rational rather than an emotional basis of understanding for the opprobrium of leprosy. The effort was subsequently reinforced by a later study (*Int. J. Lepr.* 1970, 38, 294-307) in which we noted and documented the fact that there now begins to appear in popular English language literature the use of the term "Hansen's Disease" in exactly the same context of opprobrium that we all decry when associated with the term "leprosy."

I did concur with the thinking and action of the Citizens' Committee in this matter, though not having been responsible for it. The action was of interest to me in that it gave "experimental" support to my evaluation of the problem.

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