

PRIVATE COOPERATION IN THE CAMPAIGN AGAINST LEPROSY IN BRAZIL

by

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Since colonial times, laymen and religious workers, either individually or through organizations, have given aid to Brazilian leprosy patients. There are legendary individuals who, because of their dedication to those who suffered with this most afflictive of all diseases, have been haloed, almost as if they were saints.

Among the private organizations, which, since the time when Brazil was a colony of Portugal, have rendered excellent service to these most avoided of all sick people, is the Sisterhood of Candelária. For almost two hundred years, it has maintained in Rio de Janeiro the *Hospital de Lazaros*.

In 1913, the *Associação Santa Therizinha do Menino Jesus* was organized in Brazil to give material, social, and moral aid to the leprosy patients in colonies or lazarets. This Association was the first of its kind and was founded and directed in São Paulo by Dona Margarida Galvão. In one of her regular visits to the sick, they themselves asked that, instead of giving all the help to them, she give a part to their abandoned children who because of the stigma of the disease of the parents were avoided by everybody. In 1927, this Association built the first preventorium in Brazil, the Santa Therezinha, for receiving healthy children of leprosy patients.

In 1917, at the initiative of Sra. Mathilde de Macedo Soares, the *Associação Protectora dos Morfeticos* was organized for the purpose of founding a modern leprosarium. It acquired considerable land on which the *Colônia Santo Angelo* is now situated.

In 1926, nine years later, the *Sociedade de Assistência aos Lazaros e Defesa contra a Lepra* was founded in São Paulo by Sra. Alice Tibirica who became its first president. The principal object of this society, according to its by-laws and objectives, was to aid interned leprosy patients, promote hospitalization of new patients, and construct new buildings at the colonies.

Thus the S.A.L. of Santos, in 1928, built a large building to care for 100 patients from that municipality; and the Liga de São Lazaro of Bauru, having administered a colony for some time, organized what is now the *Leprosario-Colônia de Aymores*.

In 1932, the Society in São Paulo, in cooperation with eight

other societies in Brazil, organized the *Federation* which assumed the task of coordination of all efforts. Three years later, this *Federation of Societies for Assistance to Lepers and for Defense against Leprosy* was transferred to Rio de Janeiro. It was only in this year (1935) that the campaign against the disease assumed its present nation-wide proportions.

At first, only one of the eight societies gave as the major aim of its program, the care of healthy children of leprous parents. In all others the major purpose was to give aid to the patients themselves, and occasionally to their families. The societies were not yet concerned with building of preventoria.

Also, there was, until 1935, no coordination of effort in the fight against the disease. The few societies were doing only a part of what they should have done. There was no central coordinating agency.

The year 1935 marks a new epoch. In that year, the new Board of Directors of the *Federation, S.A.L.*, sought the cooperation of the most noted leprologists of the country and sanitary officials. These gladly gave scientific support, and helped in planning a major attack on leprosy throughout the country.

The Federal Government was now planning a national crusade against leprosy along lines corresponding to the conclusions reached by the Committee of Hygiene of the League of Nations which declared: "It falls to the government to take care of the lepers, providing for them model leprosaria and colonies, and furnishing adequate treatment." The care of the children abandoned when leprous parents are interned was recognized as a most urgent part of the program, to be taken care of by private collaboration.

The *Federation*, therefore, planned the construction of at least one preventorium in each state of the Union. The plan was presented to the Minister of Health, Dr. Gustavo Capanema, who endorsed it completely. He requested the organization to assume, throughout the country, the care of the families of leprous patients, to look after the welfare of their healthy children; and, at the same time, to give social aid to the interned.

Thus the *Federation* assumed its new tasks of:

1. Organizing new societies for the aid of leprous patients and their children.
2. Reorganizing on the new basis the old societies, stressing as their first obligation the care of the healthy children of the leprous parents.

3. Intensifying throughout the country the campaign against the disease, organizing educational campaigns, with the aid of the press, radio, moving pictures, and lecturers.
4. Carrying out educational-financial campaigns for the building of preventoria.

Intensive work was begun in 1936, officers of the *Federation* traveling in the first year over six states, and raising more than \$60,000 for the beginning of four preventoria. Since then, year by year, the work has gone on in the coastal cities and towns and in the interior. The sick are visited. Local authorities are encouraged to build colonies, according to the plans of the Federal Government. Best of all, the conscience of the people in general is stirred in behalf of this work of patriotism and human solidarity.

In every state and territory of Brazil educational-financial campaigns are carried on for the building of preventoria. In addition to the money raised by public-campaigns, new interest is aroused in the work. A new tenderness is created towards the children in the "Educandarios," as the preventoria are designated, to avoid anything that in the future might impede the success of the child of leprous parents.

In these campaigns, from 1936 to 1946, more than \$8,963,789 was raised for the building only of preventoria, in addition to large amounts for the construction of churches, community halls, and athletic fields.

In 1936 a project was organized for the building of preventoria sufficient to take care of all the children, each "home" to have modern buildings and installations. These were eligible for subsidy, spontaneously offered by the Federal Government. From 1939 to 1947, the Government has given \$15,368,785 directly to the *Federation* for use in construction of 26 preventoria.

Today we have 152 societies, all federated and at work in the field of social service. All societies in Brazil follow the aims and purpose of the *Federation*. All work in harmony with the sister-societies throughout the country, carrying out faithfully the purposes as expressed in their by-laws, ignoring differences in race, color, religion, or political doctrine.

All the societies strive to carry out as best they can the five purposes as expressed at the first Congress for Social Assistance to Lepers in 1939, which are as follows:

1. Social assistance for the interned leprous patient.
2. Assistance for the needy families of the leprous patients.

3. Care of the healthy children of leprous parents in preventoria.
4. Assistance for the cured patient upon leaving the colony.
5. Education concerning the disease.

In July, 1945, the second Congress for Social Assistance to Lepers was held to establish firmly the plan of the five purposes, to study new methods of work, and to enlarge the fields of service. It was resolved to designate the preventoria, not as preventoria but as "Educandarios," "Institutes," "Colleges," and so forth. Today we have in full operation twenty-five such institutions and an additional one is operated by the State of São Paulo. Most of these are doing outstanding work in educating the healthy children of leprous patients. This had been voluntarily and spontaneously assumed, but it was officially confirmed by the following presidential decree (No. 4837) in October, 1942:

The President of the Republic, according to the power conferred by Art. 180 of the Constitution, decrees:

"*Art. 1.* The Federation of Societies for Assistance to Lepers and their children, and for Defense against Leprosy is recognized as a helpful institution of a private nature, in permanent cooperation with the National Leper Service. This recognition is extended to all the societies associated with the Federation.

"*Art. 2.* It is understood that the principal duty of the Federation and its affiliated Societies is to found and direct in all the national territory, preventoria for the purpose of caring for and educating the healthy children of leprous parents and of assisting with this education when it can be done at home.

"*Art. 3.* The Federation and the affiliated Societies will maintain themselves and enlarge their work by means of public collections, private contributions, and official financial aid. The Federal subsidy, and that of the States, shall be given annually.

"*Art. 4.* The Federation will be governed by its own by-laws which should be approved by decree of the President of the Republic. Each federated society will have its own by-laws."

What this "care and education" means, can be seen from the results shown in the majority of the preventoria. Two things are still lacking: personnel sufficiently well trained for the administrative work, and more money in order to raise the standard of living of the interned.

In 17 of our 25 "Educandarios," the internal direction is entrusted to lay-workers, and in 8 to religious orders. Experience seems to show that, in all countries studied, as well as in Brazil, something more than mere kindness and good-will is necessary to educate children for life. We need educators who can take children incapable of living without supervision, and prepare them to

be successful and useful citizens. We want to keep the children healthy in body, mind, and spirit; tolerant and worthy to live in a country of the culture that Brazil has today.

As to conserving a healthy mind and spirit, perhaps the greatest difficulty is found in the visits of the children to their sick parents in the leprosy colonies. This is the major psychological problem faced by those who direct our societies. Often the parents demand the visits of the children. The children, on the other hand, when they have confidence in their teachers, do not fail to show the harmful effects of these visits on mind and spirit.

Fortunately many parents, especially mothers, prefer only to exchange letters with their children, or to speak by telephone, and to cherish photographs, rather than to see in the young eyes the terror and affliction, as the children consider what may be the future of those parents — and, naturally, of themselves.

Many physicians cooperate wisely with the societies in avoiding this disaster, since modern psychology shows how these sorrowful impressions and fears cripple the child's mind and spirit permanently. The policy of the Federation is to space or avoid such visits as much as possible, consenting to them after the age of twelve, and only when requested by the child. In some states the regulations of the Leprosy Service do not permit children under fifteen to visit the colony. Among the 25 preventoria, only one allows children to visit the parents once a month; five permit a visit twice a year for children over five years of age; and five allow a visit at Christmas for those over fifteen.

When the "paroled" are permitted to leave the colony, and the physicians consent to the children living again with their parents, the local society furnishes a new home and gives moral and material aid.

Among the children who have grown up at the preventoria, we now have many who have gone out to work, married, and who have healthy children of their own — children strong and beautiful, thanks to what was learned in physical education in the preventoria. Some of the girls are teachers, some nurses, some in public or domestic service. The boys are to be found in the army and navy, in industry as mechanics and factory-workers, and in offices of the public service. More than 50 who have finished the courses at the "Educandarios" are now studying in professional and secondary schools.

The interned children always take part in public educational parades, just as do the children in other schools; and they receive

visits from groups of other students. All this may seem unimportant from the educational and prophylactic point of view, but is very important when we remember that, only a few years ago, the children of leprous parents, even though they were strong and well, could not attend a school or play with any other healthy children in the neighborhood. No law closed the door of the educational establishments against them, but it was always easy for the director to say that there was no more room.

The right that they now have to study, march, and live side by side with other healthy children was gained by great educative efforts, corporate and individual, on the part of the 7000 noble women who labor devotedly in twenty states and two territories of our great country. They have been helped always by enlightened physicians and laymen who collaborate with them in the work.

One of the most difficult tasks of the societies is to care for the family of the indigent leprous patient when he is interned. Personal visits are made regularly to the family, even when living at a distance, in order to study the needs first hand—material aid, house-rent, food, clothes, medicine, and moral support. Everything possible is done to make the life of the leprous patient in the colony tranquil, knowing that somebody is taking care of his family. About 10,000 persons have received such help.

Also, to the patient himself, isolated in the colony, our societies try to give social attention, furnishing many of the little needs for which the government cannot make provision. Thus our societies have built churches and chapels, community houses, halls for libraries and diversions, workshops, and athletic fields. Also the societies constantly give radios, victrolas, material for sports and games, books, records, tools, shoes, clothes, and smaller gifts. The societies also organize both civic and religious fiestas, especially at Christmas, Easter, Carnival, and such occasions.

To give an idea of what is done only in social work for the patients and their families, let us look at the figures for 1946:

For maintaining the prevention-homes	\$258,250
For leprous patients themselves	185,150
For assistance to families of leprous patients	21,227
Total	<hr/> \$464,627

In the current year an intense campaign will be begun to raise funds for the endowment of the societies, so that they may work in tranquility, with less worry about possible deficits that arise with increasing prices.

Thus the people themselves and their government work together in an undertaking of great significance, humane and Christian. At the same time, our scientists and leprologists are cooperating with enthusiasm in the task of doing everything possible to free our country, once and forever, from the terrible scourge of leprosy.