

## INTERNATIONAL JOURNAL OF LEPROSY

Vol. 4

JULY-SEPTEMBER, 1936

No. 3

## ORIGINAL ARTICLES

LEPERS AND LEPROSY 1

By Perry Burgess

President, Leonard Wood Memorial (American Leprosy Foundation) New York City

Prior to addressing a meeting in Shanghai, of doctors and laymen interested in leprosy, I was asked to give a title to that which I would say. After having spent five months in travel in Japan, the Philippines, Java, Malaya, Indo-China and China; after seeing many thousands of lepers in out-of-the-way places, living under every imaginable condition from comparative luxury to abject squalor; after seeing them under conditions where they were receiving the very best care that medical science affords, and on the other hand where there was indifferent treatment by willing but untrained people (or, as in a great many places, no treatment whatsoever)—with this background the only title I could think of was "Lepers and Leprosy."

In dealing with leprosy it is important to have in mind that there are two distinct problems involved. The first is concerned with giving food and shelter to people who are disintegrating into loathsome helplessness. The second, and by far the more important, is that which is concerned with finding the means of eradicating the disease itself.

An address presented before the joint session of the American Society of Tropical Medicine and the American Academy of Tropical Medicine, St. Louis, Missouri, November 21, 1935, and also before Medical Section (N), American Association for the Advancement of Science, December 31, 1935 (St. Louis).

It is generally accepted that there are not less than three million lepers in the world, and if we were able to detect all those in the earlier stages of the disease the number probably would be much greater. Of the positive cases in institutions probably about fifty per cent are incapacitated for work, and a pitiful handicap is placed on the others, since with few exceptions the product of the leper's toil has no market. No well person wants that which his leprous hands have produced.

The leper's state, especially in the advanced stage, is such a pitiful one that hundreds of thousands of dollars, and hundreds upon hundreds of kindly disposed lay-workers, have been forthcoming to make easier the lot of old men, young women, little children—people whose fate could, by no stretch of imagination, be more miserable.

I have visited some twenty countries where leprosy is found, and in none of these did I fail to find something, and in many places a great deal, being done by governments or private institutions-and in most cases by both-for the physical needs of the leper. However, we have in the main only begun to work at leprosy, since probably not more than two per cent of the world's total of victims of this disease are in any kind of leprosarium. And all too often these leprosaria are nothing but asylums, in which no pretense is made of giving medical care to the inmates or of trying to get at the solution of the problems presented by the disease itself. It seems incredible, when one stops to think of it, that pretty generally we have thought that much work was being done for leprosy because much money was being spent on feeding and housing lepers. It seems tragic to see great numbers of lepers herded together, often with nothing being done for them medically; to see literally millions being spent for subsistence and often nothing for research. It is toward correction of that condition that we bend our energies.

I have visited leprosaria in which were as many as a thousand men, women and children stricken by this disease, not a single one of them receiving medical attention of any sort. In an isolated ward of a general hospital I saw a young man who had been an inmate of one of the leprosaria, and who had pleaded that he be brought to the hospital so that he could be treated. From a leprosarium, mind you; and even so the treatment being given him was one that has long been discredited by practically every modern leprologist. On the other hand I visited one place in Southern China

where the lepers had built hovels for themselves among the tombs of a cemetery, as in Biblical times, using for materials frail and perishable branches of palms. In this place I found a clinician and a bacteriologist with modest but adequate laboratory equipment, and examinations were being made and treatment given with care and intelligence.

With twice as many new cases of leprosy developing each year as there are inmates in all the leper colonies in the world, I am convinced that the very fact that so much money is being spent to care for lepers often serves as an actual barrier to any considerable sum being spent in the more important basic studies of the disease. It is much like attempting to win a war by the single expedient of hospitalizing the wounded. It is humanitarian and right to hospitalize the casualties if we can, but when a war is on the essential thing is to win it and thereby prevent other casualties.

Segregation has been generally considered as the only means of eradicating leprosy, but with probably not more than two per cent of the lepers of the world in isolation it must be quite obvious that segregation will never solve this problem. I do not want to be misunderstood in this matter of segregation. I believe thoroughly in it as welfare work, and where it can be practiced one hundred per cent it may prove an effective measure. Norway and Sweden are frequently pointed to as countries where that has been done. However, I do not believe that the evidence is indisputable that even in these instances segregation was the sole factor that led to the diminution of the incidence of leprosy, since the disease has practically disappeared from all of Europe where only seven hundred years ago there were not less than 2,000 homes for lepers.

One must admire the efforts being made in the Philippines, and if the Philippine government can continue to expend for this purpose the sums that have been spent in the past, reduced somewhat by the establishment of agricultural colonies now being proposed, this will constitute probably the most thorough experiment as to the effectiveness of isolating lepers from the well population that we have ever known. However, we are compelled to grant that after over thirty years of this heroic segregation there is no striking evidence that the number of clinically observable lepers has decreased. In this same connection I wish to pay tribute to the campaign now under way in Colombia, where the government is making every effort to place all

of its lepers in a single colony. In that country it is even proposed to burn the houses in which lepers have lived if a practical method of indemnification can be found.

As a world eradication program, however, segregation is both impractical and useless. How then can we proceed effectively against this disease that for centuries has been one of the greatest curses of the human race? I would urge the building, in every country where leprosy is a serious problem, of at least one central institution, manned by medical officers with sound scientific background. These institutions may have few or many patients, but it is essential that there be enough for research. These centers should perform a three-fold service: first, carry forward investigative studies on the nature of the disease; second, make available to local doctors and institutions reliable information as to the best that is known with respect to treatment; and third, control the propaganda of the country to the end that it may be trustworthy.

We must bear in mind, however, in contemplating this problem, that leprosy is a world-wide disease which appears under greatly differing conditions of life. Therefore there is, in my opinion, the necessity for—in addition to what is proposed for the individual countries, and what is now being done in many of them—an international organization that shall not view the matter from the peculiar conditions that exist in any one particular country, but shall study the facts of the disease as presented in different countries the world over. The Leonard Wood Memorial directs its activities toward that phase of leprosy. The usual lines of research are being pursued by this and other organizations through individual scientists. We are carrying on bacteriological, pathological, clinical and biochemical studies.

While I believe that these fields of investigation are important and cannot be neglected, they must, however, depend largely on individual inclinations and "hunches." Something in addition is necessary. As a layman I can offer no opinion as to what may be possible with respect to other diseases, but in the case of leprosy I believe I am justified in holding the opinion that there is not only the possibility but the basic need for a thoroughly organized, centrally directed, world-wide, simultaneous, prolonged investigation of the environmental conditions of the leper—climate, food, social conditions, family history, contacts, etc. In other words, a world-wide

epidemiological study of all the factors that, by the farthest stretch of imagination, could possibly contribute to the transmission of the disease. It must be clear that had such studies been carried on when malaria began to be studied, it would have been discovered, long before it actually was, that the anopheles mosquito is always present when there is malaria, and this fact would have led straight to the villain in the piece. Since leprosy exists under such varying conditions we must seek to learn whether there is not always some common factor present when people become lepers.

In my travels through leprosy countries two things have impressed me above all others. First, this matter of segregation already referred to, and second the contradictions of conditions under which leprosy exists. I came to the conclusion that it was possible to make almost any statement about the disease and contradict it by actual example.

One of the beliefs that is most commonly held is that leprosy is not hereditary. Certainly the weight of evidence seems to be on that side.

One raw, fog-ridden day I traveled up a winding river along low muddy banks in Southern China. What the English doctor accompanying me dubbed "Her Majesty's" barge, a small sampan propelled by two Chinese lepers, had been sent for us. We stepped ashore in the slippery mud at the landing place and were escorted through the old colony, which accommodated some six hundred lepers. A young Chinese boy carried my cameras. He did not look like a leper but, as owner of the cameras, I had some rudimentary interest in knowing whether he was or not. I learned that he was the son of a leper, was born in the colony, had been nursed by his leprous mother and had lived in the lepers' dormitories. He had not contracted the disease. Upon inquiry I was told that there were ten such people in that one place.

In Southern China there exist entire villages, established by lepers driven from their own communities. They have not been permitted to marry people outside their villages. I was told by American doctors that in some of the places it was impossible, after three generations, to find a single leper. Frankly, I think this requires much more careful investigation, but apparently there has been a great decrease in the number of cases, whether or not it is true that the disease has entirely disappeared. However, it is noteworthy that, despite the

fact that it has been for so long accepted that leprosy is not hereditary, several scientific workers are expressing doubt that this is true, and since the necessity for revising long-held beliefs in connection with other diseases is not uncommon, it is my opinion that the question of heredity must also be subjected to more thorough study.

Is leprosy easily contracted? The general idea of laymen is that it is highly contagious. Some time ago I had a motion-picture cutter in New York work on some film of the Culion leper colony. In spite of the fact that the particular print that he was working on was made in his own laboratory, he provided himself with cotton gloves before he would touch it—"just," as he rather sheepishly explained, "to be safe." On the other hand this last summer we had occasion to bring a leper to the office of the American Leprosy Foundation in New York City. Not one of the girls in our office had the slightest fear of this man. This was, of course, because of the fact that their work had given them some knowledge of the disease and of how slight is the danger of infection.

How justifiable is this great fear of contracting the disease? The case of adults becoming lepers is apparently so rare that some leprologists go as far as to maintain that it is only contracted in childhood, though this opinion seems hardly justified. The last American to be a patient at Culion, for instance, was an ex-Spanish War soldier who had served in the Philippines. He developed leprosy several years later, and he advanced to one of the most shocking stages of disfigurement it has been my misfortune to see. Cases are fairly common in which the patient apparently could have contracted the disease only after childhood.

The weight of evidence seems to be on the side of the opinion that leprosy is not easily contracted. I personally know scores of workers in the disease in every part of the world. The number of them who have contracted the disease is very small, and the few cases that are known can usually be explained.

I visited a small, old leprosarium in Johore in the Non-Federated Malay States. Here were about two hundred patients. Until a few years ago six or seven female nurses and other workers, nonlepers, lived in the colony, ate with the patients, and slept in the dormitories. Not one has contracted the disease. At Culion where the leper population has numbered thousands since its founding in 1906 and

is 7,000 at present, there has always been a large group of well people, doctors, nurses and others, numbering several hundred. Until recently there had been no instance of any of them becoming leprous. Recently a clerk who constantly handled money of the patients has become a positive case, but he had at least one relative with leprosy. In New York City there are twenty-five or so cases all the time, and never a secondary case, I am told, has arisen in the city. On the other hand there are places where this disease, having gotten a foothold, has swept through the community like an epidemic.

One day I boarded an interisland steamer to go from Honolulu to the leper station at Kalaupapa. The boy who had taken my bag around to the cabin which had been assigned to me came back to say that there was a woman in the cabin. When the purser investigated he found she had come over from Kalaupapa on the last trip, and having occupied that cabin had assumed that she was to have it on the way back. Since she had come from the leper colony I made inquiry as to who she was, and discovered that she was the wife of one of the lepers and traveled back and forth regularly. Although I am not at all squeamish, going in and out of leper homes without any thought of possibly contracting the disease, at the same time I very generously said that, so far as I was concerned, this woman could occupy the cabin, since I did not intend doing so. It is interesting, however, that there was a case of a well person living with a leper and not contracting the disease, a not infrequent occurrence.

One of the most interesting conditions I have encountered was in Colombia, where there are about 7,500 patients in three leprosaria. These are all to be concentrated at Agua de Dios, which will then be the largest leprosarium in the world; today there are about 5,000 patients in this institution. Until 1931 the law permitted a leper to bring his entire family to the leprosarium, and a house was provided for him. Today there are 2,000 of these well people, and in every case there is at least one leper living in the house, with no attempt to segregate him from the well members of his family. The only segregation practiced has been that the entire family was confined to the leprosarium and could go outside only with permission—a permission, however, that has been frequently granted. Practically no leprosy has resulted, actually a fraction of one per cent of the population.

Why does leprosy occur in one country and not in another? We don't know the answer to that, and if we did know we probably would be hot on the trail of the solution of the mystery. Why in certain countries is it found only in definite foci? For instance, in Jamaica most of the leprosy comes from two parishes, while in Puerto Rico it comes chiefly from three cities; and in Naguabo, the city from which most of the cases come, a large number of them occur in two streets in the poorer section of the city.

Why do we find it flourishing among the Malay countries—the Philippines, Java and the Malay States—in about equal proportion? Why do we find in Java low swampy parts of the country with much malaria and no leprosy, and contiguous territory, high and dry, with no malaria and much leprosy? Why is it that in certain provinces in Southern China one-tenth of the entire population are lepers? Why is it that in that country it is found both low down in the low, damp valley and sea-coast regions and also up in the snows of the mountains?

Congested population—is that it? Then why is it that with twenty-five or more lepers living at all times in New York City, it is said that there is not a case on record of an individual contracting it in the city? The answer is not racial. I doubt whether the Chinese of Singapore live any more crowded together than those in Chinatown in New York City or San Francisco. I am told that much the same conditions hold in London and Paris as in New York City—a few cases present all the time but no secondary cases.

Why do we find it assailing the Eskimos of Iceland, the Hottentots of Africa and the Polynesians of the South Seas? Why do we find it disappearing from Europe where it flourished only a few hundred years ago, and find still a million cases in China where its existence goes back to the beginning of history? Why is it that certain states in our own South have not a little of leprosy, with a thousand cases in the entire country? Why is it that in 1856 one hundred and seventy Norwegian lepers settled in Minnesota and today the disease has practically disappeared? We do not know. We only know that the locales of leprosy are far-flung and differing, but up to the present we do not know the reason.

Is leprosy curable? Leprologists are very chary of the use of the word "cure," as are those who deal with tuberculosis. But

progress of treatment has been so slow that until about two decades ago very few had been released as "arrested cases." Now, from many institutions throughout the world, increasing numbers are released each year. A discouragingly large number of those paroled relapse. In the Philippines about 3,500 patients have been dismissed during the last ten years as bacteriologically negative. The disease has recurred in about one-half of these. Apparently this is not due solely, if at all, to the fact that these paroled people go back to the same conditions of living as those from which they came. Very recently there has been conducted at Cebu an interesting experiment in this connection. Five young men, paroled from the Cebu leprosarium, were taken into the home of a Catholic priest as house boys. This was done for the purpose of seeing whether living under hygienic conditions, with proper diet, would prevent relapse. All but one of these became positive again within a period of from four months to four years. The one who did not relapse after a two-year period is still quiescent, but this was practically a "burned-out" case when paroled.

The most that we can say about the effectiveness of treatment is that it seems very probable that clinical arrest has been effected in many early cases, and not a few that were more advanced, but we are a long way from having a real specific for the disease.

At Carville I was shown four leprous children, all of one family. Their ages ranged from six to thirteen years. Six years ago the mother was diagnosed as having leprosy, which would have been just about the time the youngest child was born. This child, who presumably was in closest contact with the mother, was the most severe case; the others varied according to their years, the oldest being the lightest. Also at Carville I talked with two women who had been negative for many years, the older one for fourteen. She and her sister have remained at the leprosarium as employees, since they have no other means of support. They were members of a family of nine; the father was seventy years of age, the mother fifty-eight, and there were seven children whose ages ranged from twelve to twenty-seven years. When the sister who was telling me the story was quite young she married a man who was found later to have long been a leper. Upon their marriage this man came into her home and lived with the family, and after four years he died. Within six years all the members of the family were in Carville as patients. An investigation on the part of the uncle failed to disclose that there had ever been leprosy in the family.

We think of leprosy as occurring usually among people of a low economic level. However, I was much interested to learn from one of the leading dermatologists in Havana that, in treating some 1,800 patients over a period of three years, patients drawn from the middle and upper classes, he had discovered thirty-nine cases of leprosy. During this same period about an equal number of patients were seen each year at the skin clinic of the general hospital, but among them only about one-third as many lepers were discovered.

And so one might go on interminably pointing out facts which, at least on the surface, seem highly contradictory and mysterious. The question which I raise is: if such contradictions do exist may they not be very significant? These very contradictions, or seeming contradictions, appearing under such independent and varying conditions, possibly can be made to deliver into our hands that factor or those factors that must always be present when an individual becomes a leper, whether it is in Galveston, Texas, or Canton, China.

The foregoing facts are some of those that have influenced us to undertake the world-wide epidemiological campaign already referred to. We shall select as the director of this branch of our studies a man of unimpeachable scientific capacity. We shall determine, through the personal visits of the director, those strategic places throughout the world where units of investigation should be set up. This study will accept nothing that is not proved; it will overlook nothing that could possibly be the cause or a partner in the cause of leprosy. It is proposed to conduct an epidemiological study in leprosy that for thoroughness will have had few counterparts in the history of medicine.

We will seek to know eventually—and we do not deceive ourselves by believing that any such program is a short one—just what the conditions were in Europe in the Middle Ages that do not exist today; what conditions exist in New York City that do not exist in Manila. We shall seek to know the habits and conditions of life of people stricken with this unspeakable disease. From such a world-wide study certain things must eventually come. Here and there facts will be observed that will suggest clues, definite leads for the bacteriologist, for the biochemist, for the clinician.

Here, too, will be clearing houses of information and inspiration that inescapably will be felt in lifting the consciousness and improving the medical knowledge and practice in the various countries. It will be easier at least to bring information as to the best that is known; and that one improvement, I can assert from personal observation, would be worth all that such a campaign will cost.

Originally this Leonard Wood Memorial was created in memory of a great American, for the purpose of building certain buildings in the Philippines and carrying on certain limited laboratory investigations. But almost from the beginning the opportunities and necessities have forced us into a wider field—the international field.

Now comes this program, bigger in its conception than the entire original purpose that brought this organization into existence, but a program which we believe is basic to the whole antileprosy campaign. This disease, that lays such hands of horror on little children, on fathers and mothers; that tears apart families and sends beloved ones into exile, shunned and abhorred by their fellows, was old when Hannibal led his army across the Alps and when Christ walked on the shores of Galilee. It stalks through scores of countries and through limitless centuries, a spectre of loathsome horror, defying the power of present knowledge.

I believe that this Leprosy Foundation, the organization of a country that knows little about the disease, has adopted a program that holds real promise. We, therefore, to the extent of our financial ability, will leave no scientific step untaken that holds any promise of finding the ultimate solution of this age-old curse of the human race.