

The Problem of Reincorporation into Society of Exleprosy Patients

TO THE EDITOR:

In the year 1944 we had the good fortune to know one of the best leprologists the world has ever seen, Dr. Ernest Muir, who was for many years Sir Leonard Roger's inseparable collaborator and who together earned enough merits in Western Europe to deserve to be called "Fathers of Leprology ROGERS and MUIR," as Danielssen and Boeck had been designated by some in Northern Europe. Together they also accumulated much information about India which has always been considered as the place with the highest prevalence of leprosy.

Muir also deserves credit for being a pioneer in the histopathology of leprosy, considering it fundamentally important in the study of each patient.

It was especially Muir who insisted repeatedly after our first contacts that we should become members of the International Leprosy Association. He naturally succeeded in his purpose, and then asked us to write a report for the IJL describing the leprosy conditions in our peninsula at that time.

The situation could not have been worse. We only knew lepromatous patients with "facies leontina" and some neural patients, terribly mutilated. Most of them were interned in the hospitals, and the few who were not segregated were hidden. We had not yet begun the leprosy campaign which was just going to be initiated by the Spanish dermatologists. Our report was published in the IJL, Volume 15 (1947) 178-182. We tried, briefly, to illustrate that even from remote times the Spanish motivation was profitable to the culture and even to the world's hygiene, always propagating far more good than bad.

At that time leprological matters were far more advanced across the Atlantic in South America than in any of the European countries and fortunately, a large commission of Spanish dermatologists the following year went to Argentina, Brazil and some of the other South American countries. They also visited Cuba, Mexico, U.S.A., Philippines, Hong Kong and so on.

We regard among our teachers Jose M. Fernandez, Guillermo Basombrio, Baliña, Argüello Pit, Castañe Decoud, Quiroga and other Argentines; the Brazilians Agricola, Rabello, Souza Lima, Souza Campos, Azulay, Bechelli and many others; the Mexicans, Latapi, Barba Rubio, Samuel, and Dra. Rodriguez; the Venezuelans, Vegas; Rodriguez, Lara, Manalang, Chiyuto and others from the Philippines. They all taught us a great many advances on leprology which, though it may seem strange after several European wars, were unknown not only to the Spaniards but to the whole of Europe. We say strange because, unless we are wrong, the first scientific knowledge of every science and also leprology awoke in our old continent. The vacuum in this knowledge, in my opinion, can only be imputed to the omni-ous effects that spread from every war.

The fact is that as soon as we returned from our overseas study trip, we began doing early diagnosis of leprosy, now recognizing early forms which we formerly had ignored. Then, we were fortunate enough to be among the first in obtaining the recently discovered sulfones (at that time) with which we obtained good results. Immediately afterwards, with a better organization not only of the sanitary problem but also of the social problem, we could draw to us leprosy patients and whole families who formerly hid themselves from public health actions.

It has been a long time since we first began the census of patients, relatives, and contacts, studying them in four aspects: clinical, histopathological, bacteriological and immunological. We had begun with 600 patients, and in the year 1962, with the collaboration of most of the Spanish dermatologists, we had already studied more than 7,000 patients and three times that number of relatives and contacts by the above methods.

During our annual investigations we found that many of the patients were cured and there were very few cases of reinfection.

With the collaboration of all Spanish dermatologists, the "Patronato Social Antilepro-

roso" (Antileprosy Social Patronage), the "Dirección Gral. de Seguridad Social y Minusvalidos"¹ (National Health Service) and some other institutions interested in these problems, we have been able to change radically the social situation of all those who suffer from leprosy, which is no longer mutilating and deforming, and to correct as well many of the stigmas which in other times justified, in some way, the terror that this disease caused.

When everything had improved in many aspects, we still had much difficulty in reincorporating leprosy patients into society. We heard some of our colleagues say over and over again that we would never succeed in getting this reintegration, but now in these latter years we are persuaded that they were wrong.

Many years ago, when we were in Fontilles we busied ourselves with the work orientation of patients so that they began to work in different jobs while they waited to be healed in the hospital. At the same time we tried to redirect them socially, thinking of the day when they would go out. We soon had the satisfaction of hearing that in some endemic areas the patients who came back from Fontilles appeared to be different from when they had been there, and also some had acquired new knowledge that they did not have at the beginning of their disease. Although the social and labor conditions had improved, it was however very difficult to find them new houses and work when they needed it. As we first tried to procure work for them, some enterprises such as RENFE, for example, gave them a kind of pension but the patients were not allowed to return back to work.

In 1955 we founded the association "Amigos de los enfermos de lepra" (Friends of Leprosy Patients), and in 1970 this officially became a part of the Raoul Follereau Foundation. We surrounded ourselves with honorary and dedicated social workers and we soon began to find modest houses which we offered gratis to the expatients. They left these as soon as they could afford to buy their own houses, so that these houses would be once more at the disposal of the associa-

tion and could be occupied by other expatients.

Among the various jobs found for expatients, our favorite has always been that of industrial washing and ironing. Therefore, we have built a factory that the "Dirección Gral de Seguridad Social," whose collaboration has always been very useful to us, declared on 15 January 1975 to be "Taller protegido de utilidad pública" (State protected factory of public utility). This factory is exempt from every kind of tax, and the government also pays us 50% of the social insurance of the valid expatients. According to the law, these factories must have 49% healthy employees. We have working in our factory about 40 expatients who earn wages at their jobs and who enjoy the privileges of social insurance as all workers do. At the beginning they were happy and satisfied with these measures, but in a year's time they began to ask for less work and higher wages. That proves that they consider themselves men and women equal to any other worker and naturally with the same rights to go on strike, etc., which is a great step in the social rehabilitation of these people.

From the foundation of this factory in 1974 we have had a total of about 85 expatients working there. Some of them (about 30) after a time with us found work in other factories in Madrid and the provinces, and we have news from them saying that they are quite pleased and satisfied. Others, however, tried to find employment and after having been rejected several times came back to us. That only goes to show how well Raoul Follereau knew the social situation of these persons when he regretted that, "... a leprosy patient, though cured, is a leper for his whole life."

In spite of everything, we can say that the social problems of these patients has changed very much in their favor.

As time goes by, the number of cured leprosy patients increases, and our workhouse has proved to be insufficient to include everyone. Once or twice we have thought of erecting other factories different from the one we have so that expatients could choose among different jobs. However, we all know to whom we owe the success we have achieved with our admired factory, to Agustín López Manjón, a modest official but very competent and well qualified, who has de-

¹The general director is José Farre Morán, of whom we are very appreciative.

voted his whole time (and we could almost say "his whole life") to this purpose. We naturally would not risk opening another workhouse unless we could count on a monitor of his preparation and qualities. Therefore, we have already built a new factory with the same characteristics as the other but with ten times its capacity.

The eradication of leprosy is more difficult in some regions than in others. In our opinion it is an easy task in those countries which are highly developed; here we can mention the Scandinavian countries as a good example. But in order to reach the long wished for eradication of leprosy, as important as the health services are, perhaps even more important is the social problem. To this end we have organized several activities.

In collaboration with the National Health Service, we have organized basic courses in leprology for scholars and people without any previous knowledge of the disease, as well as more advanced courses, given by leprologists and social assistants who work with these people, in order to develop social workers (usually members of the "Amigos de los enfermos de lepra") whom we later send to the endemic provinces in Spain

where they make a social and economic study. More specifically, in the first province checked we found 17 new cases in a total of about 400 families interviewed. Also, due to the close relations of our association with several dermatologists there have been some cases of people who come to us fearing that they suffer from leprosy or even from other dangerous skin diseases such as ichthyosis, with the hope that we might help them.

We keep in touch with most of the associations all over the world with similar interests to ours. We are pleased to say that there are a large number of them. We wish these associations all the best and encourage them to surpass us, while we take the opportunity to beg them to share with us their ideas; and we invite them to visit us, wishing to serve, if not as a model, at least as a stimulus.

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