

Preserving the History of Leprosy

Eliminating leprosy is an important goal, but so is ensuring that records survive.

Dr. Jo Robertson is Research Officer for the Global Project on the History of Leprosy, an initiative of the International Leprosy Association, funded by The Nippon Foundation. The project, which began in October 2004, is developing a database of locations where leprosy archives can be found in order to facilitate historical research into leprosy in the period after 1800. It is based at the Wellcome Unit for the History of Medicine at the University of Oxford.

What is the purpose of the project?

This project is dedicated to ensuring that the history of the work done against leprosy is not forgotten and that the voice of the person affected by leprosy is heard. The strategy is to create and develop a database of references to historical documents; build an infrastructure for future research that will attract and encourage researchers across the world to undertake work on the modern history of leprosy; and include references to existing collections of audio and video interviews relating to leprosy so that pathways will be created for researchers interested in the personal voice.

Anwei Law from IDEA is working on the oral history side of the project, where the strategy is to develop advice to assist others to undertake oral history work; instigate networking among oral historians interested in leprosy; and give some initial assistance in cases where valuable particular individual histories are in danger of being lost due to age or illness.

How did you become involved?

My doctorate *In a State of Corruption: Loathsome Disease and the Body Politic* is on the representation of leprosy in colonial Queensland. I started my doctorate as a result of the documents that I saw in the Queensland State Archives. The correspondence and reports about people who had been isolated on islands off the coast of Queensland were extremely moving, and I could not understand why I could not find any voices that objected to the isolation of these people.

Why is this work important?

As the campaign to eliminate leprosy moves toward achieving its goal, leprosy work is being integrated into general health services. As this happens, the concerted and specific work that has been developed and spans more than two centuries will move into a different phase.

Time will only tell if leprosy will ever disappear, but if the transition into the general medical health service is not successful, it is not inconceivable that the skills and knowledge

gained against the disease may some day need to be revived. Without careful management, however, this knowledge is in danger of being lost.

Even though published research work is easy to access, the records that provide a more detailed picture of that research may not be available to future researchers because the copious data that has been compiled will have been discarded.

Independently of medical research priorities, leprosy also provokes many questions of political, social, cultural, national, and international interest, making the preservation of records an imperative if these issues are to be explored.

Above all, this is a disease that has caused misery for 3,000 years. As it fades away, we mustn't allow a record of that human suffering to be lost, so that future historians can interpret the significance of this milestone for mankind.

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Do many historical records exist, and which in particular stand out?

So far our database has over 200 sites where substantial repositories of historical records can be located, and there are many more that have been identified, but not yet added to the database. There are many really impressive collections of records, and it is getting extremely difficult to single out any one collection.

What is interesting is how it is possible to see a "story" — one facet of the leprosy story — emerge out of a simple list of documents that are held in a single collection. In addition, when the collections are put together, it is also becoming possible to trace the larger story of leprosy in single countries and also internationally.

One of most exciting finds has been the wonderful collection at the Gandhi Memorial Leprosy Foundation in Wardha, Maharashtra, India. The foundation was established in 1951 and prided itself on taking an "entirely different approach to the problem of leprosy."

The plan was to select a small area for control and eradication work; to examine every individual and put all leprosy patients on oral DDS; to follow their contacts; to undertake repeated surveys for finding out new cases; and to segregate infectious cases wherever and

LEPROSY FACTS

- The modern history of leprosy studies began in 1847 with the publication in Norway of *Om Spedalskhed (About Leprosy)* by Daniel Cornelius Danielssen and Carl Wilhelm Boek. In the early 19th century, Norway had the most leprosy patients of anywhere in Europe.