



Books

From boat racing to the love of leprosy elimination

As a child growing up in a village in India, I have seen people begging outside temples who only had stubs of hands and feet, caused by the enervating disease leprosy. India declared prematurely that it had eliminated leprosy in 2005, but the nation has documented the return of this disfiguring infectious disease in early 2009. WHO states that 208 619 new leprosy cases were registered globally in 2018, even though the prevalence rate is less than one in 10 000 people around the world. According to WHO, about 60% of the total global new cases of leprosy in 2015 were from India. The main reasons for the comeback of the disease are low awareness about the disease, as well as stigma and discrimination of people suffering from leprosy at a societal level.

These reasons are not new in the social history of leprosy around the world. If the references to leprosy in the Bible and Buddhist texts refer to the same disease that now we know is caused by the bacterium *Mycobacterium leprae*, then we can be sure of the long tradition of common knowledge on the stigma around leprosy in society. People with the disease are often ostracised from society. In the 1940s in Japan, when Ryoichi Sasakawa's girlfriend knew that she might have contracted leprosy, as it might have happened in any other part of the world back at that time, the young girl disappeared from Sasakawa's life, leaving him in limbo. Thus, Sasakawa made his life's mission to help to cure both leprosy in patients and the stigma around it at societal level, writes his son Yohei in his book *No Matter Where The Journey Takes Me: One Man's Quest For A Leprosy-Free World*, an English translation by Rei Muroji of the original Japanese book titled *Zanshin*, published in 2014.

Yohei Sasakawa goes to great lengths to describe not only his own journey from travelling with his father to leprosariums (ie, places where people with leprosy were cared for), but also his experience of being a Goodwill Ambassador of WHO for leprosy elimination. The author also deliberately makes attempts to sanctify the social image of his father, who started his philanthropy initiatives from the roots of gambling. It is endearing to read how Yohei adored, if not revered, his father, who was involved in the legalisation of boat racing in Japan under the auspices of the Japan Shipbuilding Industry Foundation, which was established in 1962 and later renamed in 2011 as the Nippon Foundation. The Foundation has worked within Japan and overseas for various philanthropic reasons; however, its primary focus has been on leprosy elimination.

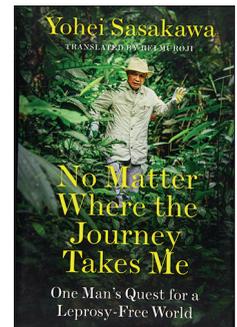
"Some people may wonder if this one experience [about his fled girlfriend] in his youth was the entire motivation behind my father's creation of what became such a large organization. In this anecdote from the past I sense

the kind of 'righteous indignation' so characteristic of Ryoichi Sasakawa", writes Yohei Sasakawa. "For my father, the fight against leprosy was a fight against discrimination and a fight based on his righteous indignation against discrimination." Ever since his childhood, young Yohei witnessed his father touching and embracing people with leprosy. This touch was both a scientific and a social message that these infected people were to be treated in a humane way and that leprosy does not spread through touch as people often fret; a mood that Yohei Sasakawa vividly carries throughout the book.

Alongside his accounts on the origins of the Nippon Foundation and its work in leprosy elimination around the world, the author charts a detailed history of how he and his father, along with several notable figures in Japan and abroad, worked together for leprosy elimination. For example, they worked towards scrapping the Leprosy Prevention Law in Japan, which was discriminatory, then bringing the early leprosy drugs promin and dapson into the country with the help of people such as Morizo Ishidate (who is referred to as the "father of chemotherapy for leprosy in Japan"). The Foundation championed its work through Yohei Sasakawa's own travel in over 90 countries and his liaison with politicians and organisations such as WHO. While the author takes pride from his father's legacy, he also lulls between the pride of his own work as a philanthropist and the humility of his inspiration coming from people other than his father, like Mahatma Gandhi, the pontiffs of the Vatican, and the 14th Dalai Lama.

In this personal history of leprosy elimination that is based partly on memoir and partly on biography, Yohei Sasakawa gives the readers almost too much food for thought and urges them to accept that he has successfully followed his father's footsteps. He followed his father by raising awareness among politicians and the high commissioners of the UN through his Global Appeal initiative that leprosy must be seen not only as a public health problem but also a human rights issue, to fight stigma and discrimination; by providing funding from the Foundation and procuring free multidrug therapy medicines to eliminate leprosy in various developing countries; and by constantly reiterating three messages, namely, "that leprosy is curable, that treatment is free, and that it is wrong to discriminate". Yohei Sasakawa's journey and message is clear and important, even at present, and hopefully will inspire other people to take to heart the plea of individuals with leprosy who are still experiencing stigma in their countries.

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