

A Quilter's Tale

Leprosy broke up her marriage, but Yang Qian Mei was able to make a fresh start.



These cloth bags are among the products made by Handa Quilt.

Reference

* Handa Rehabilitation & Welfare Association was founded in Guangzhou, China in 1996 to promote respect and dignity among all human beings, especially those who have personally faced the challenges of leprosy.

I was born into a peasant family in a mountainous area of northern Guangdong, China in 1958. I came from a happy home and married a man from a nearby village in 1980. We had three children, one son and two daughters. I managed the land and household while my husband worked as a truck driver. Eventually we bought a two-story home. Life was sweet.

One day in 1991, my husband commented on changes in my face. When the doctor told me I had leprosy I couldn't believe it. "I have never done bad things so why should God treat me like this?" I cried. I lost all confidence. I refused treatment because I knew it would affect my family. My face and legs began to develop ugly blisters.

Finally, in 1994, I was forced to check into hospital. In two years, my husband only came to see me once. I excused him, thinking that he was busy working to support the family. The children had gone to live with their grandparents, but I later heard they had been sent back home by my brother-in-law because I had leprosy. I wanted to visit them, but my face was dark from drugs, and I was afraid. At age 10, my oldest daughter had to drop out of school to care for the younger children. I was in despair.

After two years I was cured, but didn't dare go

back home because my face was still discolored. I worried constantly about my family.

Then I had the chance to join a sewing class started by Handa* in Guangzhou and learn a skill. I worked very hard and was able to do well. The other women were much younger than me and I felt that I could comfort them and be strong for them.

In July 1996, my husband came to see me. I was so happy, thinking he had come to take me back. To my shock, he asked for a divorce, and I discovered he was living with my niece. I felt as if I had been stabbed, and could not understand why hardship followed me around like this. If it wasn't for leprosy, this wouldn't have happened.

Handa encouraged me through the hard times and gave me the opportunity to work. I became a teacher in the Handa Quilt project and now help to design new products. I am fast on the machine and don't mind working overtime to make items for sale in bazaars and other outlets. People admire my work and I have regained my self-confidence.

Recently I married a man who himself had leprosy. He is very attentive and loves me very much. He has accepted my children as his own. Life is sweet again. ■

PARTNERS

ZEN RYO KYO

Zen Ryo Kyo, or the All Japan Hansen's Disease Sanatoria Residents' Association, dates back to 1951, when its forerunner, Zen Kan Kyo, an association of sanatoria patients, was founded. Zen Ryo Kyo represents the interests of residents of Japan's 13 national leprosy sanatoria, established between 1909 and 1945 in accordance with government policy to confine leprosy patients. Leprosy was considered a "national disgrace" and with the passage of the 1931 Leprosy Prevention Law, all who contracted the disease faced compulsory exclusion from society.

From the beginning, Zen Kan Kyo (renamed Zen Ryo Kyo in 1996 when the Leprosy Prevention Law was abolished) was a movement initiated and managed solely by and for individuals with leprosy. From the day it was established, it was an expression of the collective will of the residents, at first to seek a drastic revision of the Leprosy Prevention Law, later to improve the quality of their lives, and then to restore their integrity and dignity in the face of stigma and prejudice. It continues to address



Zen Ryo Kyo members meet with Japan's health minister (right) on October 20, 2003.

issues that are relevant to the needs of the times, particularly in educating and enlightening society not only about leprosy but also the broader issues of human dignity and human rights.

From a high of 12,092 patients in 1958, there are 3,522 residents in the nation's sanatoria as of March 2004, with an average age of 76. As Zen Ryo Kyo's membership ages and its numbers diminish, it is determined to inspire Japan's younger generation to create a society free of prejudice and discrimination, to leave an accurate record of the history of leprosy in Japan, and to see that the remaining residents live out their lives as they wish.