Professor shares pain of facial deformity
Talking key to breaking down barriers and abuse

By MIWA SUZUKI

In 1957, Toi and Masaharu Fuji, a son they named Teruaki, a literal translation of which is "shining bright."

Little did they know then that, within a few years, their son would be described as a "monster."

A pink, round mark began to show on Fuji's right cheek when he was 2 years old; it was an omen of the harsh discrimination he was to endure later in life.

The mark was an angioma, a benign tumor consisting of dilated blood vessels.

By his early 20s, the red spongy collection of blood vessels had spread to his nose and midforehead with the swelling around his upper lip dragging like a miniature elephant trunk.

Having been spat at on the street on a number of occasions, Fuji has nevertheless seen his affliction lead to a medical vocation.

Now 46, Fuji currently serves as a professor of nursing science at the state-run Kumamoto University.

With the release of his autobiography, titled "Face of Destiny," in October, Fuji became a torch bearer for the roughly 1 million people in Japan who have deformed faces.

"Many of those people tend to cloister themselves at home as others look daggers at them," Fuji said in a recent interview.

"I urge those people to go out and tell others 'I suffer, my heart aches.' I have been saying the same thing for two decades... but there are finally moves to break down the invisible wall" between the disabled and others, he said.

Despite moves toward a more tolerant society, former Hansen's disease patients at the Kikuchi Keifuen Sanatorium recently found themselves to be targets of discrimination.

A hotel at a spa town refused to honor reservations for 22 prospective guests from Keifuen in November, seven years after Japan ended its 89-year forcible seclusion of those afflicted with Hansen's disease, commonly known as leprosy.

A court ordered the hotel to pay a fine of ¥20,000, the same penalty as that given for a speeding offense.

The Sanatorium dates back to 1910, housing some 500 individuals suffering from aftereffects or complications from the disease.

"Some could not even be taken back to their hometown after they died," Fuji said, adding that the Sanatorium keeps the ashes of 1,200 such people.

"Patients still adopt aliases, fearing relatives might be tracked down and suffer discrimination," he said.

It was only in June 2001 that the Diet apologized to Hansen's disease patients who had suffered forcible sterilization, forced abortions and other human rights abuses.

Fuji knew only too well the pain of being judged on one's appearance.

He used to keep his face down on his way to kindergartens, so that others would not notice his mark.

On his first day at elementary school, a boy called Fuji a "monster," sparking off mass chanting of the name among the other children.

When he was 14, Fuji was in acute pain because of the tumor.

"I woke up one summer night, burning as though a kettle of boiling water had been pressed against my face. The mark was swelling, with tiny rashes spreading over it," he wrote in his book.

"It was a horrifying scene, like small worms wriggling under the skin... Something was getting unruly in my face." He even feared that his face might explode someday.

Fuji entered the economics department of the private Chuo University in Tokyo in 1973.

With the right side of his face deformed, he was never invited to parties where there would be girls, while students would move if he sat next to them.

This discrimination continued when he started looking for a job.

Although he was a top student armed with a written recommendation from the principal, he was rejected by 50 companies.

"The financial business is a service industry, so we can't hire a monster like you," said one company recruitment official.

The turning point in Fuji's life came when he attended a Red Cross lecture and a doctor urged him to pursue a medical career, arguing that he could understand the pain and sorrow of those with serious diseases.

He underwent a 10-hour operation in April 1982 to remove the bulk of the tumor at the hospital where the doctor worked, and later started working at the computer department there.

Yet even the surgery left a bitter memory - one of the doctors involved in the operation kept the removed tumor as a specimen without his consent.

This infuriated Fuji, who vowed to explore the insensitivity shown by some doctors toward their patients.

He entered Chiba College of Health Science to study nursing science at age 28, becoming a professor at Kumamoto University in 2000.

Fuji also visits schools to outline the unfairness of discrimination, letting children touch the soft, warm tumor through which his pulse can be felt.

Although he has come to view the tumor as being "not so bad," Fuji admits he sometimes yearns for a face free of abnormalities.

He and eight others jointly published a book in December 2002, titled "Don't stare at me."

One of them, Saori Abe, a woman in her 20s who suffered from complete hair loss and worked as a wig counselor, committed suicide just before the book reached shop shelves.

"It is a harsh reality that we (with facial abnormalities) still live our lives laboring under a heavy burden," he said.