100 years in the fight against fear

Once a dumping ground, Hansen's disease center is no longer 'end of world'

By CHRIS FRINK
Westlake bureau

CARVILLE — In the spring of 1956, Julia Rivera Elwood was 15 and on the way to becoming head cheerleader at her high school in the Rio Grande Valley of Texas.

Before the school year ended, she was diagnosed with leprosy, then torn from her close-knit family and exiled to a fenced-in hospital complex in Louisiana with another 350 patients near the isolated Mississippi River community of Carville.

The gates were guarded and barbed wire topped the fences.

"I thought the end of the world was here and I didn't know how to stop it," Elwood said.

"I thought I was going to be here until I died. That was very hard for me to take," she said. "I wondered what I did to deserve this."

Officially, Elwood's new home was called the U.S. Public Health Service Hospital, but most people knew it as the Carville leperarium.

The hospital opened in 1894 after the state leased the remains of a 1656 plantation as a site for a new Louisiana Leprosarium.

The formerly tumble-down plantation is today a collection of clinics, offices, homes, dormitories and churches sprawling over 330 acres.

More than three miles of covered walkways connect most of the white-plastered buildings. These roofed and screened corridors protect people walking, or on bicycles and in wheelchairs, from the sun and rain as they move about among the buildings.

Huge oak trees spread shade over much of the grounds. Pecan trees litter the grass with nuts every fall.

Vegetable gardens dot courtyards with a variety of produce that reflects the patients' varied ethnic backgrounds.

More than 90 percent of the hospital's residents are from the world's tropical regions: Southeast Asia, Central and South America and the Caribbean.

The hospital even has its own golf course and softball field.

The hospital, now officially the Gillis W. Long Hansen's Disease Center, named for the Louisiana congressman who helped fund it, celebrates the 100th anniversary of the first patients' arrival this month. Leprosy is now known as Hansen's disease in the United States.

Like so many hundreds of other patients, Elwood's trip to Carville was not voluntary.

"The Texas public health people made me come. They said I was infectious," she said. "I wondered what I did to deserve this."

Leprosy patients who arrived in earlier, less enlightened times often
A patient at the Hansen's Disease Center in Carville rides his wheelchair on the grounds of the hospital. The hospital has 132 permanent residents.

The first patients, five men and two women, were rescued from the slums of a privately run New Orleans "pest house" after a campaign by a crusading newspaper and several physicians.

The Leper Camp board leased the Indian Camp Plantation on this remote point surrounded on the worlds only one who could do the job. The nurses lived in cottages around the hospital.

Hansens Disease Center in Carville

She and Elwood saw other changes at the hospital over the years.

"Things at this hospital were very bad in 1965," Elwood said.

"The medical officer in charge ordered all the patients to stay in bed," Elwood said. "We were sick so we helped us in pajamas and in bed.

Patients rebelled and began a petition drive to replace the doctor. Within a year he was transferred," she said.

The hospital, which cares for about 1800 patients, was closed in 1966.

"Under Johnwick's administration, patients were allowed more days and weeks to the outside world," Elwood said.

Before, patients were kept in the hospital for months and years. Now, they can go outside for a few days and see the world.

"That's under consideration in Congress," said Elwood. "It's way up in the air.

In the meantime, "for the patients, it's going to be business as usual," Jacobson said. In the next 10 to 15 years, as the number of permanent residents dwindles, the hospital is going to be downsized to where it's not feasible to stay here," he said.

Remaining patients would be moved to a nurses' home-like facility in Baton Rouge, Jacobson said.

A two-year experiment in which the Hansen's disease complex was shared with the federal Bureau of Prisons ended in August.

The bureau leased unused parts of the complex for a prison hospital, but left it because it did not have enough room.

"The Bureau of Prisons felt that they could take over the whole facility in two to three years," Jacobson said. "That was not possible.

The hospital's research arm moved to leased space at the LSU veterinary medical school to help make room for the prison.

About 45 people work on Hansen's disease and tuberculosis research.

"We're making an impact worldwide," Jacobson said.

Sister Francis DeSales, who will remain as a nurse after she retires, said she wanted the hospital to remain open.

"We need Carville, the beauty of our place helps patients to recuperate," she said.

"You can't help loving these patients," she said. "They're just part of our family."

Advocate staff photo by Michael Hults