



Hansen's Disease on a Louisiana Plantation

CAPT Rita K. Chow, USPHS (Retired)

In the 1800s, leprosy, one of the oldest diseases of humanity, needed to be controlled in the United States. In response to this public health need, the Louisiana Leper Home was created at the abandoned, dilapidated Indian Camp Plantation at Carville--an isolated Mississippi oxbow site about 80 miles from New Orleans. On November 30, 1894, under the cover of night leprologist Dr. Isadore Dyer, accompanied the first seven patients who were stealthily transported in a coal barge towed by the *Ella Hawkins* tug with provisions, bedding, and 80 beds and moved into dilapidated, abandoned wooden slave cabins. Under the care of a resident doctor, the number of patients increased to 20—still housed in the dismal slave cabins.

Over a year later, on April 27, 1896 the first four Daughters (Sisters) of Charity of St. Vincent de Paul volunteered, after accepting the contract for "the nursing of the patients and the household management," including the kitchen and laundry, and each Sister would serve for \$100 a year "for clothing and other incidentals." The 30-room plantation classical Greek Revival-style mansion was reserved for the Sisters, but only two rooms were habitable. Bats, rats, lizards, and snakes abounded everywhere. Undeterred by adversity, the Sisters kept an ax and lantern by their bedside at night to attack the water moccasins whenever they spiraled up the bedposts. They focused their nursing tasks on cleaning and dressing leprosy sores, washing tubs full of revolting soiled bandages, and during times of drought and dry cisterns, used wheel barrels to obtain water from the Mississippi.

Malaria, hardship, and suffering took its toll on the Sisters and patients. Subsequently, nurse administrator, Sister Benedict Roche (1901-1919) joined the Carville staff and was able to obtain appropriations and made such capital improvements as a water plant, new patient cottages to replace the slave cabins, hospital to increase bed capacity, laboratory, operating room, pharmacy, clinics, screening, and fencing, so it became a fenced-in colony. The afflicted patients were isolated for a number of reasons. One was due to the fact that other than close family contact, exactly how leprosy was transmitted was unknown. Also, the public feared the disease and its complications of leontiasis (lion-like) facial disfigurement, amputations, and blindness. Depending on the type of leprosy, some patients coped with such lepromatous complications as madarosis (loss of eyebrows and eyelashes), paralysis of the eyelids, failing vision, edema, and polyneuritic pain. And there was no definitive pharmacologic therapy. And since Louisiana had the only state-supported leprosarium, health authorities in other states wanted to send their patients there.



Sister Veronica in the Eye Clinic

Signs of Societal Change

The first significant step toward change came through the 64th Congress in 1914 when Bill H.R. 1751 was introduced to establish a National leprosarium. However, it was not until after World War I that the singular historic event happened. On January 3, 1921, the Federal government purchased the Home that then had 90 patients and approximately 337 acres and converted the Carville site into a National leprosarium, the US Marine Hospital #66. Administered by the US Public Health Service (USPHS), it became an outstanding self-sustaining rural community that included its own power plant, sewage and chlorinated water systems, laundries, Protestant and Catholic churches, incinerator, staff residences, patients' recreation building, well-equipped Fire Department, and large two-story concrete hospital (Infirmary). The hospital contained a first-class operating room, Dental Clinic, laboratories, Dressing Clinic, and more. There were also buildings with individual bedrooms for ambulatory patients and other buildings for occupational therapy, a shoemaker's shop, bicycle repair, school, and even a patients' printing office for *The Star* magazine. The Carville leprosarium attracted numerous patients nationwide. For example, between December 1, 1894 and January 1, 1946, 1,517 patients were admitted. By 1946 Dr. G.H. Faget, its medical director, opined that the Carville leprosarium could be the most modern and finest in the world. The Daughters of Charity continued with their multiple roles under the Civil Service System. The medical staff consisted of six USPHS medical officers, a dentist, and monthly consultants who specialized in dermatology, orthopedics, and neuropsychiatry.



Daughters of Charity, Carville, 1922



Medical and Nursing Staff, 1942

The Life-changing Sulfones

In years 1941-1947 may be considered the first therapeutic revolutionary period because of the initial outstanding achievement of discovering the sulfone drug efficacy on leprosy. Sulfone drug therapy with Promin (diamino diphenyl sulfone), Diasone (sulfoxone sodium), and Promizole (thiazo sulfone), made possible a turning point. They replaced chaulmoogra oil (ethyl esters of hynocarpic acid). In 1941 patient Betty Martin called intravenous Promin "a miracle" because she and her husband Harry experienced its dramatic trial results of feeling cured. After World War II began, patients contributed to the war effort--from selling or buying war stamps to planting victory gardens. The Martins were fruitful with their fig and plum trees, grapevines,

tomatoes, corn, beans, peppers, and eggplants. The good results from administering Promin and Diasone enabled increasing numbers to be discharged. For instance, in 1945, 34 patients were discharged with the arrested disease. As part of their extensive care, patients remaining received about 15,000 such forms of physical therapy as thermotherapy, hydrotherapy, and massage to help relieve nerve pain, heal ulcerations, and restore muscle functions.



Hydrotherapy Session

An Ever-Widening Influence

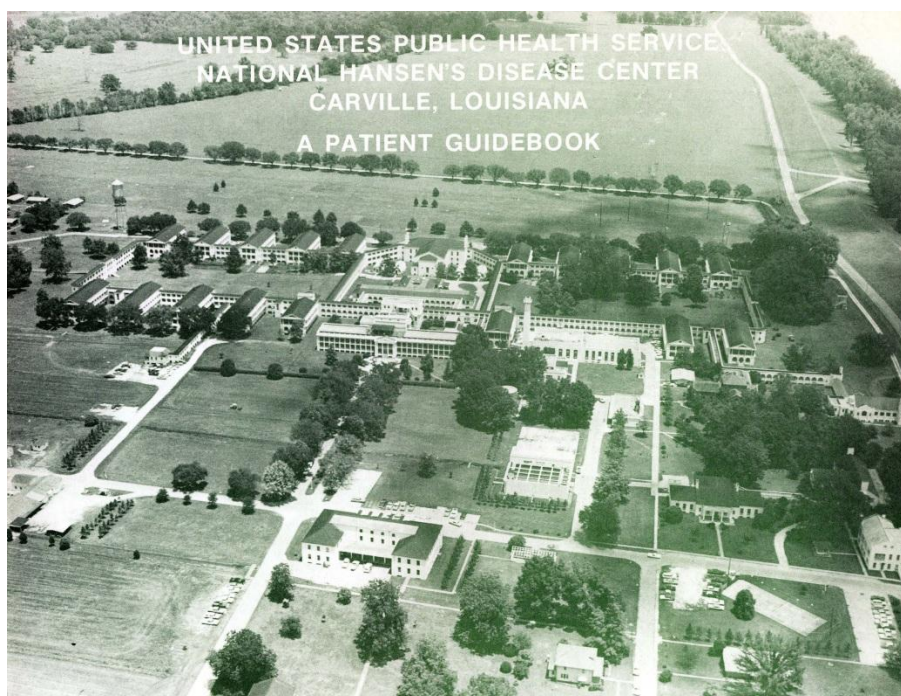
Progressively, Carville developed as a local, national, and international postgraduate educational center for clinical information on leprosy—attracting medical students, physicians, dentists, and nurses. A diagnostic advancement was made in 1959 by Dr. Charles Shepard of the Center for Disease Control. He discovered that *Mycobacterium leprae* bacteria would multiply when injected into the nude mouse footpad. It was followed by another breakthrough in 1968 by Drs. Waldemar Kirchheimer and Eleanor Storrs who demonstrated that the nine-banded armadillo developed disseminated leprosy when inoculated with *M. leprae*—making it an ideal research animal for leprosy studies.

The second wave of the therapeutic revolution came in the sixties with more experts and specialists augmenting the staff and the use of combined therapies of rehabilitation eye, foot, and hand surgery; physical therapy; research; and pharmacologic regimens. Additional invaluable scientific accomplishments increased the number of effective anti-leprosy drugs. Contributions included Browne's work with clofazamine (B663), a riminophenazine derivative, for active lepromatous leprosy and erythema, Sheskin's thalidomide, and rifampin.

Clinical Outreach and Research

During the eighties, Regional Centers to care for leprosy patients in their communities became well established for providing continuity of care in key States across the nation including Hawaii, California, Washington, Illinois, Massachusetts, New York, Florida, and Texas. By then the disease designated as "leprosy" had been replaced by Hansen's Disease (HD), the preferred name of patients who dreaded being called "leper." (The HD name honors Gerhard H.A. Hansen, the Norwegian discover of *Mycobacterium leprae* in 1873).

During the five years (1984-1989) when I was assigned there, the facility was still in the height of fulfilling its mission of compassionate patient care and education about the disease for health personnel and students from many states. Subsequently, when I accepted the assignment to be an Assistant Director of Nursing (Night Supervisor) and its first Director of Patient Education, the facility was known as the National Hansen's Disease Center (NHDC), and later renamed the Gillis W. Long Hansen's Disease Center. In 1984 we formed an interdisciplinary Patient Education Committee. And together we believed that patients should be taught health promotion, self-care, disability prevention, and physical fitness.



Aerial View of National Hansen's Disease Center

Consequently, being familiar with the form of exercise called "Body Recall" that originated in Berea, Kentucky and noting that there was a Body Recall Demonstration Team in nearby Baton Rouge, LA., I gathered such NHDC staff talent as Julia, the school teacher to play the piano and Sister Rose Anthony, RN, who always seemed to thoroughly enjoy "leading the line" of a Mardi Gras parade--albeit this one would be for long-term care patients in wheelchairs. On the same day I invited the Demonstration Team and contracted an agreement with Marie, their leader/instructor. For \$100 she gave us permission to have a copy of her exercise music and to videotape the demonstration for our staff and patient for educational purposes.

Later an interdisciplinary team of three USPHS officers, a physical therapist, occupational therapist, and I, conducted a pilot study on Music Therapy and Movement. We

were curiously a motley group of nationalities—all attempting to move our limbs rhythmically in unison, but no one expected hilarity. One amiable male patient with a double amputation would wear his prostheses to class. During leg adduction-adduction movements, the majority of the class would move together in one direction; he would follow the leader's instructions, but his artificial limb fitted with a shoe would flop over in the opposite direction. This unintentional impact titillated the group, including the patient himself. The mirth spread rapidly. In fact, a patient came regularly to watch us exercise. He laughed so hard that he would need to wipe his tearful eyes with a handkerchief. We had unanticipated the bonus of laugh therapy. After three months, we achieved measurable improvements in upper extremity Range-of-Joint Motion of all participants, despite their disabilities of blindness or bilateral leg amputations. And at the celebratory certificate award ceremony, the patients proudly demonstrated their new ability to stand. And they saluted to honor the presence of NHDC Director Dr. John R. Trautman, renowned for his professional knowledge, administrative and diplomatic skills. Deeply touched, he immediately returned the salute and responded, "I salute you."

In essence, worthwhile collaborative team efforts, combined with research, pharmacological therapeutics, and rehabilitation therapies, contributed toward limiting the crippling effects of HD. Through years of unrelenting research in improving the treatment and diagnosis of HD, patients were lifted from the shame, social stigma, depression, and loneliness of a devastating disease to an opportunity for full assimilation into communities to heal and thrive.



Infirmary, 2011

About the Author

Rita K. Chow, CAPT (Ret.) USPHS, served as Director of Patient Education and Assistant Director of Nursing, National Hansen's Disease Center, Carville, Louisiana, from 1984-1989.

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