

Directory of History of Medicine Collections

Organization Name: National Hansen's Disease Programs Museum

Organization Type: Museum

Address: LOCATION: 5445 Point Clair Road, Carville, LA MAIL: 1770 Physicians Park Drive

City: Baton Rouge

State/Province: Louisiana

Zip/Postal Code: 70816

Country: United States

Telephone Number: 225-642-1950

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Web Site: <https://www.hrsa.gov/hansens-disease/museum/index.html>

Online Catalog:

Other:

Abstract: About the Museum: The museum's mission is to collect, preserve and interpret the medical and cultural artifacts of the Carville Historic District and to promote the understanding, identification and treatment of Hansen's Disease (leprosy) by creating and maintaining museum displays, traveling exhibits, publications and a Web site in order to educate and inform the public. The vision of the National Hansen's Disease Museum is to support the National Hansen's Disease Programs in its effort to enhance the public's understanding of the history, treatment and rehabilitation of leprosy in the United States, and to commemorate those who lived at the national leprosarium as patients, as well as the health care professionals who made medical history as they battled leprosy. Researchers must register in advance. With approval, some copying may be performed on site by staff.

Holdings: Scope and content: Collections span the entire history of the treatment of leprosy (Hansen's disease) on this site (1894 to 1999), the Daughters of Charity's work at Carville (1896—2005) and the mission of the U.S. Public Health Service at Carville (1921—1999), Stanley Stein and The STAR Magazine (1931—present). The Daughters of Charity collections consist of correspondence, publications, photographs, and newspaper clippings compiled by the Sisters to document their mission at Carville. The collection is especially strong in documenting the everyday life of the patients. The collection includes extensive correspondence and diaries from the Daughters of Charity, but does not include medical records, nor does it include official correspondence of the Medical Officers in Charge. The US Public Health Service collections tell the history of the mission of treatment, care and rehabilitation of leprosy at the National Leprosarium by the federal government (1921-1999). Special collections include HD Teaching slides, Dr. Guy Faget correspondence and sulfone drug trials (1941-1947) and Medical Officer in Charge daybooks 1921—1960. Stanley Stein and The STAR Magazine: Patient Stanley Stein was the first editor of this patient publication. He arrived for treatment in 1931 and quickly began publishing The STAR's precursor The Sixty-Six Star-- from 1931-1934. Stein's magazine employed dozens of patients over the decades and achieved a readership of 60,000+ worldwide by the time he died in 1967. The STAR's photographs, first person reporting, and advocacy coverage makes it a useful resource in understanding the ramifications of social changes at the hospital and beyond as leprosy became a treatable disease and went from forced quarantine to voluntary admission. 1931-present. Note concerning patient names. The majority of patients at Carville took aliases when they entered the facility. This was a common practice aimed at reducing the social stigma of leprosy for the patients' families. Many patients retained their Carville name throughout their life. However some patients went back to their real names in later years. Real names are used in cases where the patients didn't take an alias or went back to their real name at some point in their lives. In cases where patients did not want their real names revealed, the patients' wishes have been respected and aliases have been retained. The collections are organized into major areas as follows: 1. Administration, 1896-1999: Annual reports and other general administrative material. Public Health

Reports; Financial Data, 1896-1980s (bulk: 1930s and 1960s). Annual financial reports and expenditures. Arranged chronologically. 2. Annals of Carville, 1934-1999: Diaries kept by the Daughters of Charity who were in residence at Carville. For the years 1934-1962, the annals were typed accounts of day-to-day activities prepared by the Sisters. (from 1962-1999, the annals are compilations of articles from *The STAR* and news clippings) Arranged chronologically. 3. HD Dissertation and Thesis Collection: Published research by graduate and professional level students focusing on the social issues, rehabilitation and psychological aspects of patients hospitalized for leprosy in the United States. Approx. 50 papers. 1960 to present. 4. HD Film Collection: Instructional films created at the U.S.P.H.S. hospital in Carville by doctors, rehabilitation specialists and the Training Department (20 topics from casting techniques to the care of the eye in leprosy) on DVD. Included in this collection are documentary films made by U.S.P.H.S. staff as well as those outside the hospital system, e.g. *Triumph at Carville*, *Exiles in Our Own Country*, *Roots of Faith*, and *Banished Living with Leprosy*. Approx 20 titles, DVD. 5. History, 1894-1999: General and topical histories of the National Hansen's Disease Programs and the Carville facility; accounts of anniversaries and significant visitors. Arranged alpha by title. 6. Hospital Facilities and Engineering: Collection of blueprints, surveys, and tools used in hospital construction and maintenance. Interesting artifacts include Corinthian capitol from Indian Camp Plantation (which served as the administration building from 1896 to 1999) and survey equipment from the 1930s. Bulk: 1920s—1999. 7. Johnny Harmon Photography Collection: Johnny Harmon was a patient who became *The STAR* magazine's chief photographer (active 1944—1957) creating a vast archive of photographs depicting patient life, activities, special events, entertainers and VIP visitors, buildings and grounds. Searchable by subject which include: The Daughters of Charity, American Legion Post, Patients School, The *STAR* Staff, Holidays, Celebrations, Medical Staff, Sports and Leisure. Film negatives, print copies and digital formats. 1944-1957. 8. Legislative History of Leprosy: A chronological compilation of federal, state and local laws that address and affect the care and treatment of persons diagnosed with leprosy. Many laws were amended due to advocacy efforts giving back to patients' rights once denied because of their diagnosis of leprosy. Digital and hard copy formats. 9. Leprosy in Literature: Patient authored memoirs and articles focusing on autobiographical accounts of living with leprosy in many cultures and timeframes. Fictionalized stories written with leprosy or Carville's hospital as a focus (by non-patients) included in collection. 1930s to present. 10. Medical Journals: *International Journal of Leprosy*, *Leprosy Review*, *Indian Journal of Leprosy*, *Hansenologia Internationalis*, *Korean Medical Abstracts*, *Revista Argentina de Dermatologia*, *JAMA*, *The Lancet*, etc., collected by the Carville Medical Library. Collection includes rare international monographs about leprosy, Bulk: 1921—2004. 11. Newspaper Clippings, 1890s to 2000: Articles about Carville and Hansen's Disease from local and national newspapers. Arranged chronologically and keyword searchable. 12. Oral Histories: Staff and patients of the National Leprosarium give personal accounts of their work and daily life here as medical professionals and quarantined patients. The collection of 100 oral histories is mostly in digital format, approximately 50% with written transcripts. About half are audio only and the balance are video interviews. Some restrictions apply. In-house access only. 1996 to present. 13. Outside Organizational Involvement: American Leprosy Missions, Lions Club, American Legion and American Legion Auxiliary; The Forty and Eight (veterans), Disabled American Veterans and Auxiliary, Lions Club, Delta Sigma Epsilon Sorority, AMvets. (Bulk dates: 1940s—1990s) 14. Patients' Life, 1920s- to present: Correspondence, photographs, news stories, documenting individual patients; photographs and programs documenting patient activities and life includes: patients' school, recreational and social activities, sports teams, musical programs, clubs, Christmas programs, and Mardi Gras celebrations. Focus on John Early, Betty Martin, Stanley Stein, Johnny Harmon, Josefina Guerrero, Gertrude Hornbostel, et al. (Bulk dates: 1930s through 1960s). 15. Publications, c. 1920-2004: Includes printed matter produced at Carville, literature concerning Hansen's disease geared toward the general reader, and reprints of articles from various medical journals. Medical Vertical Files contain over 4000 entries of medical reprints from 1920s to 2000. Focus on medical research and rehabilitative techniques of leprosy treatment. The Point Clarion newsletter, first named Personnel News Bulletin, was published by staff (incomplete—1959 to 1988 and The Question Mark, published by students of the Carville School (1949 to 2006) are included in this collection. Hard copy only. 16. Stanley Stein Archives: Stanley Stein (real name Sidney Levysen) began "*The Sixty-Six Star*" magazine in 1931 only 2 months after his quarantine to Carville. His relentless advocacy and political connections were reported on in *The STAR*. His office files have been cataloged by subject and focus on medical professionals, legislation, patient advocacy, and patient organizations and other topics of interest to the patient population. Additions to some files by patient editors Louis Boudreau and Ray Elwood. Correspondence, photographs, and journal articles. (1941-1980) 17. The *STAR*: (hard copy and online digital archives) The *STAR* Magazine was established by patient Stanley Stein and has been in publication from 1941 to the present. A complete

set of the original volumes in chronological order are searchable by printed index. The STAR is also found on the Internet at http://www.louisianadigitallibrary.org/cdm4/index_p15140coll52.php?CISOROOT=/p15140coll52. The digital index is keyword searchable and may be downloaded and printed. The STAR's predecessor publication, The Sixty-Six Star, from 1931 to 1934; discontinued due to publication of "Leper's Mass" article scandal; chronological order; hard copy only (incomplete). Also photo file index from The STAR offices organized by subject. 1931 to present. Restricted materials include unpublished clinical photos of patients and lists of patients which show real names, home addresses, and other personal information.

Collection Subject Strengths: History of Epidemiology and Infectious Diseases; History of Public Health

Other Collection Subject Strengths: Leprosy in the United States

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