The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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National Hansen's Disease Museum Committee. (L to R, back row) Mickey Templet, Alicia Hoard, Anthony Sanchez, Jr., Dr. Jim Krahenbuhl, Dr. Marion Roots, Capt. Wayne Fuller. (L to R, front row) Jane Walters and Elizabeth Schexnyder, Curator. Not pictured: Jerry Simmons and Tanya Thomassie.

Photo by Mr. Oscar Concepcion

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NOTE: Please take notice of Volume and Issue Numbers.

Stanley Stein
Founder - Editor, 1941 - 1967

The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease, 2.) Furnish vocational rehabilitation for interested patients.

Views expressed in **The Star** are those of patients of the Gillis W. Long Hansen's Disease Center at Carville, Louisiana, except in the case of direct quotations or signed articles.

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After you have read **The Star**, please pass it on to a friend and if **The Star** reaches you at a library, please place it conveniently for readers.

Editorial Policy On Terminology

The Star stands firm in its opposition to the use of the term "leprosy." We shall never abandon our campaign to secure general acceptance of "Hansen's disease." Nevertheless, the word "Leprosy" does appear in **The Star** under circumstances which we feel are unavoidable, namely: when signed articles are authored by someone who does not agree with us or when material discusses the disease prior to the introduction of the term "Hansen's disease." We dislike the word "leprosy" intensely, but we dislike the practice of censorship even more.

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National Hansen's Disease Museum

Open House November 5, 2003

Photos by Elizabeth Schexnyder

The National Hansen's Disease Museum officially opened in July of 2000 (The **STAR** volume 59, No. 3) with a ribbon-cutting ceremony attended by volunteers, employees and organizers of the museum--Mary Ruth Daigle, Sr. Margaret Brou, Julia Elwood, to name a few--as well as officials of the National Hansen's Disease Program--Capt. Charles Stanley, then Executive Officer, now Director, and Dr. Robert R. Jacobson, Director of the NHDP in 2000. The museum doors opened to show off the artifacts--originally collected in 1994 and 1996 to mark the centennial years of the arrival of the first seven patients at Carville and the arrival of the first four Daughters of Charity--it was a fine start-but there was more work to be done.

(L to R) Old friends Mary Morris and David Peltier.

(L to R) Jane Walters and Sister Dorothy Bachelot, DOC, in exhibit devoted to the Daughters of Charity.

The Mission

Two years after the official opening, the museum hired its first curator, Elizabeth Schexnyder, in 2002. "The museum's mission is to collect, preserve and interpret the medical and cultural artifacts at the Carville Historic District," Schexnyder says. "In order to fulfill this mission, and promote the identification and treatment of Hansen's disease; my plan is to create and maintain museum displays, develop traveling exhibits and make available multimedia educational programming. In order to accomplish this, first we needed a more suitable museum space." And so plans for a renovation began.

(L to R) Burnell Williams and Anthony Sanchez enjoy the "Patients' Culture" display.

The Plan

The National Hansen's Disease Museum is located in Building 12 of the Carville Historic District. Completed in 1943 as the staff kitchen and dining facility, the building went through several reincarnations over the years--from kitchen to finance department and finally the resting place for records from other hospitals that closed in the 1980's. What was to become the main exhibit space--2000 square feet of open ceiling terminating 25 feet above the visitors' head--was a cramped, claustrophobic, and dim room. It took several months just to plan the relocation of the PHS records. Each shelf was measured and weighed. "Several tons of materials had to be shifted before the room was ready for the restorative work to begin," quipped Schexnyder. "It was hard to visualize what kind of space we really had."

Once the room was cleared of old records, renovation began of the 2,000 square foot area that had originally functioned as the kitchen. The expanded gallery space and upgraded track lighting and heating and cooling system will allow the museum to show a greater percentage of its collections, to borrow important artifacts, and to host significant traveling exhibitions in the future. "We needed to take this huge step towards fulfillment of our mission and join the larger community of museums," Schexnyder said. With the renovation, the museum can now accommodate a group of 100 or so visitors at a time. The unveiling of the renovated space on November 5, 2003, to NHDP employees, patients, family, and friends proved this so.

Arcenio, Carville resident and first time museum visitor. Uniformed LA National guardsman (background) views medical artifacts

The Opening

The renovation of the old kitchen was completed over the summer of 2003. The drop ceiling was removed, revealing 25 feet of overhead space that could be used to hang flags that once flew over the PHS Hospital at Carville and provided wall space enough to accommodate large format paintings by patient/artist John Korver. Now it was time to plan for the opening of the newly renovated museum. The museum committee sprang into action. Menus were

brainstormed. Volunteers recruited. Invitations sent. On November 5, the party began. On display, were the expanded permanent exhibitions centered on medical breakthroughs in treatment and rehabilitation of HD; the medical staff, PHS, Daughters of Charity, and civil servants employed at Carville over the past 100 years; and patient culture and the buildings of the Carville Historic District. New track lighting, added to the hallway, illuminated the new "100 Years of Carville History" timeline.

(L to R) Helen Fuller, Byron Gautreau and Mary Gautreau

The opening was an unabashed success. Over 100 visitors attended the afternoon gala. The volunteers arrived and acted as docents, guiding first-time visitors through the renovated space. The Louisiana National Guard, the National Hansen's Disease Program employees, patients still residing at Carville and many who had since moved away arrived with friends and family. Several retired NHDP employees came to the opening and donated artifacts to the museum. Dr. Yoder and the Reverend McPhearson came bearing gifts of personal papers and framed artwork. Mrs. Lee Perkins donated copies of photographs of Carville before the levee was built in 1927. A special thank you to all those who donated artifacts. It was especially heartwarming to welcome Julia Elwood back to the museum. Julia was the original organizer of the Carville museum in the 1990's. She and husband Ray Elwood have since retired and moved to Texas.

And let's not forget the food! Our volunteers really came prepared to feed the hungry museum guests. Jane Walters, who headed up the subcommittee for the museum opening, with support from Mickey Templet and others, prepared a spread of finger sandwiches, desserts and drinks that kept the crowd hovering near the reception tables. Mr. Warman Schexnyder, Sr., museum volunteer--and the curator's father--drove in from Lafayette to cook meatballs, chicken wings, and sausages. Oscar Concepcion and Anthony Sanchez, NHDP employees, lent logistical assistance and camaraderie as Mr. Schexnyder cooked up a storm on the museum loading dock.

"Finally, I would like to give special thanks to the museum committee. They were available to bounce ideas against and helped me figure this whole thing out," says Schexnyder. Capt. Wayne Fuller was the brains behind the renovation; Dr. Jim Krahenbuhl organized the large format printing of the Abbott Laboratory panels through LSU, Anthony Sanchez hung flags and paintings; Dr. Marion Roots helped with administration of the museum committee; Jane Walters and Mickey Templet were the driving force behind the food preparation, logistics and invitations for the opening and Alicia Hoard is working on interpretation of exhibits. "We have a fine crew, and it showed on November 5," curator Elizabeth Schexnyder said.

Museum volunteer Warman Schexnyder drove from Lafayette to cook for the event

The Future

Now begins the next phase of the mission. With the renovation complete, the curator muses on the year to come. "Group touring and education is key. I have begun collaborating with the Job Challenge Program run by the Louisiana National Guard at Carville. We tour a platoon through the museum every week." In addition, two students have arranged to begin working at the museum on continuing the inventory of museum artifacts. There were over 3,000 artifacts in 2002. Currently the collection has increased to an estimated 5,000 items. An updated museum inventory is crucial for accreditation by the American Association of Museum-a process that is in the works and is slated to be completed by 2005.

(L to R) Warman Schexnyder and Oscar Concepcion, NHDP Recreation Therapist, cooking on the museum loading dock.

Volunteers are coming forward from the community. Mrs. Vickie Joseph of St. Gabriel has donated many hours to organize the research archives of the museum as well as make archival quality copies of the Daughters of Charity annals and letters for the museum. "Vickie single-handedly copied over 20 volumes from the Daughters of Charity archives. She's been an invaluable help," says the curator.

In the meantime, the doors are open and first time visitors, as well as those who have had a part in the Carville story, are welcomed. "Please come and experience Carville's dynamic and important history," says Schexnyder.

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Open Hours: Monday through Friday, 10 AM - noon & 1-4 PM

Note: Due to the changing levels of National Security observed by the Louisiana National Guard gatehouse, please call in advance to verify accessibility and be prepared to show picture identification.

No charge for admission. Closed federal holidays.

LEFT ALONE

DEPARTMENT OF ECONOMETRICS
UNIVERSITY OF MADRAS

Dr E. Max

Tragedies in personal life help us refine and realize our potential. I was dismissed from Elementary School as a leprosy lesion on my face became visible I never blamed the European nun who dismissed me from the convent school. Leprosy was the most dreaded disease in those days. I contracted leprosy when I was a little child in 1946 when medicine for treating the disease was not yet available in India.

I could not get admission even in the elementary school meant for the poor children. I remained at home for one academic year engaging myself in domestic works. I had an urge to continue education. In the beginning of the next academic year I appealed to my father to take me once again to the elementary school meant for the poor. (As my grandfathers were wealthy children of our families and were educated in schools meant for the rich). The Head Master of that school (meant for the poor) thoughtfully looked at me for some time and said that he could admit me only under certain strong conditions. I hastened to tell him that I would obey all the conditions. He was surprised because I was ready to obey even before knowing the conditions. He then stated the conditions. (1) I should enter the classroom only after all the students get in; (2) I should sit on the stool specially provided for me in the corner near the door.; (3) I should not walk inside the classroom even for showing my slate to the teacher who will never come to see my slate; (4) I should leave the classroom as soon as the closing bell rings; (5) I should not go near the common water pots. I religiously obeyed all the conditions and continued my education. When I was in the sixth year of schooling, deformities developed on my hands and I was forced to leave school.

I was taken to a leprosarium in a remote place where large number of grossly deformed and disfigured leprosy patients were living. God gave me great courage to live in the leprosarium. My grandmother (Ammachi) was the compassionate hand of God that took care of me. She stayed in a hut outside the leprosarium. She made great sacrifices in order to save me from the horrors of leprosy. I can write a volume on my experiences.

I secured First Rank wherever I studied - High school (Advanced Mathematics Group), College (B.Sc. Mathematical) and University (M.Sc. Mathematical Economics). In 1971 I became a Lecturer in Madurai University Department of Economics to teach the same M. Sc. (Mathematical Economics) program in which I was a student during 1968-70. I also served as a faculty for the M.B.A. program of Thiagarajar School of Management, Madurai. I represented the School of Management in the "University Teachers Program on Operations Research," at the Indian Institute of Management, Ahmedabad. I successfully completed Ph.D. (Management Science).

Madras University appointed me as Reader in Econometrics in 1976. In 1982 the University Grants Commission of India gave me the Career Award in Humanities and Social Sciences, on the basis of my academic achievements and research capabilities. I utilized the major grant carried by the Career Award for conducting a major research project on the "Economic Interactions between Leprosy, Labour Productivity and Poverty". On invitation from UNDP/ World Bank / World Health Organization Special Program (Geneva) I prepared a scientific paper on "Economics of Leprosy" and presented it in the "First International Meeting on Economics of Tropical Diseases", 1986. Harvard University School of Public Health, Boston, USA, appreciated the paper and gave me the International Award of "Takemi Fellowship in International Health" in 1987, when I was serving Pondicherry Central University as the first Professor and Head of Economics Department at Mahe. I returned to Madras University where I was appointed as Econometrics with retrospect effect from January 1, 1987. I applied for leave and left for Harvard University.

The outcomes of my advanced research on Leprosy completed at Harvard University were prominently used by (a) "World Development Report 1993; Investing in Health" (the World Bank) and (b) the International Symposium on Health held at Tokyo University, Japan, in 1988. The volume, published in USA, based on the Symposium contains my paper "Leprosy Control in India: Role of International Cooperation" as chapter 13. At Harvard I applied Econometrics and completed a research paper on "Productivity Loss due to Deformities from Leprosy in India" which was published in the International Journal of Leprosy (USA) in 1989.

I progressed very well in my profession but it was far from satisfying me. My conscience was agitating and urging me to engage myself in human service to the leprosy affected and others living in miserable conditions. I successfully completed many micro-level action-projects and got true satisfaction from my advanced research highly appreciated by great institutions and organizations. I am greatly indebted to the people, enduring various kinds of sufferings and sorrows, with whom I worked intimately. The divine joy they gave me was much greater than the small comfort and consolation I could give them. The poor- I will never get tired of saying this - are wonderful and generous.

In 1996 "The Hindu" (India's National Newspaper) prepared and published an article on me, "In the Service of the Scorned", giving an account of my works along with my photograph. The publication of this article resulted in cruel reactions from my own sisters, Kith and Kin who were ashamed of their family relationship with me. I did not mind the inhumanity of my relatives. What I could not bear with was the hatred shown to my beloved children who had nothing to do with leprosy, popularly known as "Great Disease" in India. Leprosy is not hereditary but the hatred to a Leprosy patient is heredity. A person who contracts Leprosy remains as a Leprosy patient throughout life even after getting complete cure.

God is now calling me to work for the "Divinity of Family" particularly the "Divinity of the Bond between parents and children". Recently, He put me in the most sorrowful situation that made me a Heart patient. On July 16, 2003, my beloved elder son (holding the degrees of M.B.B.S., and M.D.) left me. It was the most sorrowful day in my life. I never felt so sad when I was dismissed from the Elementary school and denied admission in any school because of Leprosy.

As soon as my beloved wife's coffin was laid to rest in the deep pit, my elder son (then 16 years old) attempted to jump into the pit so that he might also be buried. I prevented him by my right hand as I was holding my younger son Syluvai Anthony (then 7 years old) by my left hand. I dragged both of them to the grave built nearby and sat on it with my two sons and consoled them by saying, "Do not think that your Mother is dead. She is living ..... in me! Hereafter I am your Mother". Since that day, I took care of my children as their Mother, doing whatever their Mother did for them, including cooking food. God converted me into "Thayumanavan" (Man who became Mother). I realized the Divinity of Motherhood. It may be interesting to note that "Thayumanavan" is the name of a Hindu God who came in the form of the Mother of a female devotee when she was anxiously looking for her Mother to help her in delivering the first baby.

I rejected all the proposals for my second marriage and firmly decided to remain as Mother to my beloved children for the rest of my life. I value my children as the Divine Gift of God. They are most precious to me. I have great love for my children and reverence to my wife. When she was nearing death as a bed-ridden Cancer patient crying with terrible pain, day and night, she appealed to me to have a second marriage after her death so that I would not be left alone in old age. I rejected her appeal and told her that a second marriage would ruin the future of her beloved children for whom she made so much sacrifices. When she died my younger son did not know how to take food by hand and eat because his Mother was feeding him by her hand all the times, even when she was bed-ridden with great pain.

My elder son was doing Eleventh year of schooling when his Mother died. I consoled and encouraged him. He secured high marks in the Final Examination of twelfth Standard. I supported him to secure admission to Medical College. In the first year MBBS he was terribly tortured by senior students in the name of "ragging". One night he wept loudly and said to me, "Dad, I cannot endure the torture any further ..... I want to drop out of the MBBS course". On the next day he did not return home in the evening.

In the night I rushed to the medical college located at a distance of 55 kilometers from our home. I cried like a child in front of the Dean of the Medical College and Hospital begging him to give my son back to me. The police searched the entire campus of the Medical College along with me. We also searched the Hostel where the senior students were staying. We could not trace my son. On the next day my son returned home with great pain caused by physical harassments. I approached a high level police officer in Madras who took step to stop the ragging. My son could continue MBBS without any problem. He did very well in MBBS and got admission to MD (General Medicine) when his batch-mates and many of his seniors could not.

While doing MD final year, one evening my son told me that he decided to marry a girl who was his batch-mate in MBBS. I had never seen her. I had no idea about her and her family. I was in a terrible fix. I felt as if the world turned upside down. I was terribly worried about the future of my younger son Syluvai Anthony for whom I wanted my elder son to be the guardian after my death. My elder son refused to marry any other girl. He convinced me in various ways and explained to me in detail how virtuous the girl of his choice was. I had no alternative. I believed in his explanations. I was also impressed by the pleasing words of the girl of his choice. On September 4, 2002, I celebrated the marriage for which I spent a lot of money on gold and other costly things for the bride without receiving anything in cash or kind from the bride's side.

After the marriage I discovered the truth. I was totally disappointed and deeply hurt. On July 11, 2003, my daughter-in-law packed up her things and left my home. On July 16, 2003, my beloved Doctor-son left my home. I had to live alone, with chest pain, during day time as my younger son was attending college. There was no one to attend to me at home as my domestic helper was away. As her father died she had to be with her mother in her village for a month.

The very thought about the ways in which my beloved elder son was separated from me has been causing great pain in my heart though I am taking strong medication given by an eminent Cardiologist.

I am deeply concerned about the future of my beloved younger son Syluvai Anthony who lost his mother when he was seven years old. I am also concerned about the future of my elder son. I pray to God Almighty to forgive him for whatever sins he committed against me and to bless him with peaceful life.

I am praying to God Almighty to grant me life for some more years for the sake of my younger son Syluvai Anthony who is yet to complete B. Sc. (Statistics).

I have now discovered the Divine Will of God. He wants me to spare my wealth and the remaining part of my life to help the poor and to work for the "Divinity of Family" and Human Values within Families".

I have developed comprehensive meaningful spirituality, on the basis of my clear understanding of the noble teachings of Buddha, Jesus Christ, Mohammed Nabi and Ramakrishna with which we can strengthen the unifying factors and defeat the divisive forces. My article "Toward Religious Unity" carried by "The Hindu" Open Page on November 14, 2000 (the birth day of Pandit Jawaharlal Nehru) gives a part of my spiritual knowledge which can be used effectively in reforming the minds of children in this cruel world of violence and vulgar sex.

I wish to develop a "Temple of Peace" in order to provide (a) consolation to persons living a sorrowful life, particularly parents who are deprived of love and support of their own beloved children for whom they made so much sacrifices, and (b) moral education to reform and cultivate the minds of children.

Vulgar programs in Television which is accessible to all the children in rural and urban areas have been demoralizing children and making life miserable for multitudes of parents. I feel that I am left alone in my work on the "Divinity of Family". Money is no problem. I have served Universities for 32 years and I am still in service.

I need only human good-will and cooperation.

Professor E. Max
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CURRENT DATA ON PROMIN THERAPY

E. A. Johansen, Medical Director (R)
Medical Officer in Charge
U.S. Marine Hospital Carville, LA

The optimism referred to in recent reports from this hospital relative to promin and diasone treatment has continued progressively to increase. The use of these two drugs has increased to maximum. All patients except those where such treatment is contraindicated are taking some form of sulfone therapy. Clinic experience has strengthened the position of the sulfone drugs in the treatment of Hansen's disease. Promin has been in use at this hospital since March 1941. Serious toxic effects have not been observed in any patients. Promin patients continue to experience a feeling of well-being and most clinical findings of early infection are found to subside materially aftr several months of treatment. It is probable that infections of short duration respond to treatment more readily than do the infections of many years standing. However, it is becoming discouraging to certain patients to find that after four or five years of continuous promin treatment their skin smears still show Hansen's bacilli. Such findings may be observed in a patient who has shown remarkable improvement objectively. Generally speaking it is found that the leprous process does not tend to progress during treatment. Diasone has been administered at this station for more than three years. Since May 1947 the drug has been supplied in a more palatable sugar-coated tablet form, and it is felt that this form will cause less nausea than the odoriferous capsule previously used. Improvement with diasone therapy is approximately comparable to, but somewhat slower than, the improvement following promin. 179 patients are now taking promin regularly and 162 patients are taking diasone regularly. Thirty-five patients who have taken promin have been discharged to date and ten taking diasone have been discharged to date. While no claim is made that these drugs are specific remedies, they have proved therapeutically more effective in Hansen's disease than any previous treatment tried at the Carville Leprosarium. Unfortunately, they work slowly. Definite objective improvement as a rule rarely becomes manifested before at least six months of treatment. The disease seldom, if ever, appears to get worse under treatment.

Gems
(excerpts)
from past issues
September 1947

Highlights

IN THE CHEMOTHERAPY OF HANSEN'S DISEASE at the U.S. Marine Hospital.

Carville, Louisiana,

Procedure

Promin is administered intravenously. Adequate doses are not tolerated orally. It may be given intramuscularly but local pain following injection is usually severe. Since sulfones are eliminated from the body rapidly frequent administration is necessary. The recommended initial dose of promin is 1.0 gm daily. This dose is gradually increased to an optimal dose of 5.0 gm daily. Rest periods of one week duration are given every two weeks. On this dose good therapeutic results occur with a minimum of toxic effects. Promin is of low toxicity but hematuria, anemia, and dermatitis occasionally occur. Periodic blood count. urinalyses and clinical examinations are required to guard against toxicity. All patients whose red counts run under four million are given either inorganic iron or liver treatment.

A small group of patients are receiving intensive promin therapy under close medical observation. These patients receive 5 cc's of promin 3 times daily. The results to date are encouraging.

* * * * * * *

Diasone is given by mouth, daily doses varying for adults from 0.33 gm to 1.00 gm, and for children from 0.17 gm to 0.5 gm. The diasone patients receive the same laboratory checkups as the promin patients.

* * * * * * *

Sixteen patients in this hospital are currently taking promizole, a drug which closely resembles promin and diasone. Promizole is taken by mouth and is relatively non-toxic. According to preliminary report, clinical improvement with promizole has been more rapid, in some cases, than with either promin or diasone.

Doctors Faget, Pogge and Johansen have stated that "the therapeutic results thus far obtained are sufficiently encouraging to warrant further clinical study, which will be necessary before a final evaluation of promizole in the treatment of Hansen's disease can be given."

This hospital has a supply of promizole on hand but one leprologist, wishing to buy promizole for use in foreign fields, was told by Parke-Davis that the manufacture of promizole is very difficult and at present it is not being made.

* * * * * * *

The reduction in number and severity of ulcers since the inauguration of sulfone treatment at the National Leprosarium is graphically illustrated in reduced cost of gauze, adhesive plaster, and bandages used in the dressing clinics. The reduction in cost of such supplies for the last fiscal year was $7,419.50 as compared to 1940 (before any sulfone started). The cost of the promin given during that period was $6,986.00.

* * * * * * *

The action of promin in eye complications of leprosy differs from that of penicillin, in that promin helps to prevent future attacks of iridiocyclitis, while it usually has little or no effect on acute inflamations while they are in progress. Conversely, in our experience, penicillin reduces markedly the duration and intensity of an inflamatory process that is in progress, but does not seem to have any value prophylactically against future attacks. Therefore, at the leprosarium penicillin is used to abort acute attacks of iridiocyclitis as a complication of leprosy, and promin to reduce or prevent future attacks.

* * * * * * *

Medical authorities have repeatedly stated that when an effective chemotherapeutic agent is found for Hansen's disease, it may also be effective in the treatment of tuberculosis as the two chronic diseases have many parallelisms.

Drs. Hinshaw and Feldman of the Mayo Clinic have reported that, "The drugs of the sulfone series (promin, diasone and promizole) were the first preparations to succeed in actually arresting tuberculosis in the highly susceptible guinea pig. This naturally led to high hopes that sulfone drugs might be of value in the treatment of tuberculosis of human beings. Several hundred patients who had tuberculosis have received treatment with these drugs and experience has tempered early enthusiastic hopes of some physicians. The possibility that sulfone drugs may be of aid in treatment of certain unusual varieties of human tuberculosis has not been excluded, but no definite place has been found for these drugs in treatment of the usual types of tuberculosis. The use of sulfone drugs under any circumstances has not progressed beyond the experimental stages."

According to tuberculosis literature, the sulfones in tuberculosis have been given an adequate trial and are reported as of little or no value. However, a communication from Dr. Feldman to this hospital intimated that he intended revaluating promin in human tuberculosis.

The early results of sulfone therapy in Hansen's disease were somewhat disappointing, but the doctors at Carville persisted. Several Carville patients in whom tuberculosis exists as an intracurrent disease, have had this condition improved by sulfa therapy.

When the conversation drifts, as it so often does here, to the use of promin, the thought is always of the 5 gram solution used intravenously. The intraveneous injection is the original and basis treatment, but promin is not entirely confined to a "shot" and several local promin medicants have been tried with varying success.

Because of the extreme need in the eye, ear, nose, and throat clinic to adapt promin more directly to its needs, a 5% emulsion for nasal sprays and a 5% solution for nasal packs were prepared by our pharmacy, but it was found that such a weak dilution was so unstable that it soon lost its efficiency. The pharmacy solved that problem by making very small quantities frequently.

In attempting to use promin as an eye wash, a 1% solution was tried, but the stability was too brief. A 40% solution was substituted and while it was much more stable, it generally proved too irritating. The answer to maintaining a relatively stable solution and at the same time eliminating the irritation seemed to lie

in matching the solution to the pH of tears. pH means the potential hydrogen or the hydrogen ion concentration. It seems that all of the body's fluids have a definite acidity or alkalinity. This is called pH. The 5 grams of promin given intravenously are mixed in 121/2 cc's of solution. The results matches the 7.4 pH of the blood and thus eliminate severe reactions. Small reactions in the form of rashes do occur, however, and this can usually be overcome by a period of desensitizing or giving small doses of 1 gram and gradually increasing it to the full dose of 5 grams.

So having somewhat overcome the unstableness of the eye wash, the pharmacy tried to prevent the irritation by matching the natural solution of the tears. When this did not show signs of succeeding quickly, a 40% ointment with a hydrosorb base was used. This proved even more irritating to the orbs. A desensitizing period using increasing percentages of promin may be next. At any rate, the results thus far obtained seem sufficiently encouraging to advocate a continued effort to adapt promin as a local medication for the eyes.

Birth of Promin

Ten years ago five scientists sat down in Detroit and discarded a long-accepted theory on bacteria. The immediate result of their revolt was promin, a new drug. Promin is one of the sulfones, cousin of the sulfanilimides. It was developed in the search for a drug to do the same thing the sulfanilimides were doing, and do them better.

In the Parke-Davis laboratories in Detroit the five research men were looking for a weapon against tuberculosis. They were Edward Tillitson, now professor of chemical engineering at Wayne University; B.F. Tuller, now in New York; L.L. Bambas, Parke-Davis chemical research, and Leonard Doup, another Parke-Davis man who has devoted his life to the study of leprosy and tuberculosis.

The old idea was that the bacteria of tuberculosis and leprosy, which are related closely, were surrounded by a fatty or waxy "capsule", and research had been aimed at a fat soluble substance to penetrate the capsule. But, since the bacteria use substantially the same food elements and vitamins as the human body, the Parke-Davis men threw out the theory, experimentally, on the assumption that basic elements of these foods must enter the bacteria in a water-soluble form.

Promin was born of this conference, in 1937. In action, the drug sets up a virtual blockade in at least one of the essential food elements. Dr. Sweet explains that it is as if the promin were a key and the bacteria a lock. The key gets into the lock but stops the mechanism instead of operating it, thus actually starving the organism.

It was tried first on tubercular guinea pigs. Its success was overwhelming. After exhaustive laboratory tests, the discoverers were convinced they had the tuberculosis problem solved. But in clinical tests in human tuberculosis, promin was a great disappointment. It proved less effective than streptomycin. At the same time preliminary tests were being made with leprosy, and the research men turned in that direction. Tuberculosis and leprosy have many things in common.

The medical profession is cautious about the word "cure" in this instance. Because of the slow development of the disease, doctors point out, it may be years before promin can be declared a cure for leprosy.

Dr. E.A. Sharp, head of Parke-Davis' department of clinical investigation, says: " As far as we can tell, from all methods available for examination promin-treated leprosy patients are cured."

★

Editor's note:

Please note that this "Gem" has statements made 56 years ago.

A Summary of Hansen's Disease in the United States - 2002

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March 14, 2003

Introduction

The National Hansen's Disease Program's (NHDP) mission is to conduct leprosy research, educate patients and health care providers about the disease, and provide direct medical services to Hansen's disease (HD) patients in the U.S. and its territories. In carrying out this mission, the program collects beneficiary information and maintains a National Hansen's Disease Registry. The registry is a computerized database that provides useful information for epidemiological studies, administrative reports, and clinical, rehabilitative and laboratory research.

Data are collected through the cooperative efforts of health care providers and a network of state and local healthcare agencies. Patient information is collected by the health provider with the *Hansen's Disease* (Leprosy) *Surveillance Form,* which serves as the instrument for processing new cases into the registry. When the NHDP becomes aware of a new HD case, a surveillance form is sent to the provider to obtain the data needed to register the patient. Additionally, this form can be downloaded from the NHDP website at http://www.bphc.hrsa.gov/nhdp/. Registry data are also reported by various state and local government agencies through the surveillance form.

Because HD is a notifiable disease, registry data are statistically analyzed and reported to the Centers for Disease Control and Prevention (CDC). As requested, summary reports are also provided to other federal agencies for administrative and funding purposes, as well as to state and local agencies. Numerous clinical, epidemiological, and academic researchers request customized reports pertinent to their specific interests.

2002 Registry Summary

Temporal Distribution

In 2002 a total of 133 Hansen's disease cases were reported to the National Hansen's Disease Registry (NHDR), representing a 20.9% increase in the number of cases (n=110) reported in 2001. The monthly number of cases reported ranged from two (1.5%) in October to a maximum of 23 (17.3%) cases in March. Table 1 and the chart in Appendix 1 illustrate this monthly distribution.

For the second straight year there was a disproportionate number of cases reported in the first seven months of the year. Compared to 2001 in which 83% of the cases were reported in the first seven months of the year, 77% of the 2002 cases were reported in this same time period. For the four month period of April - July, 52 (56%) and 56 (42%) cases were respectively reported in 2001 and 2002. Only 21 (16%) of the 2002 cases were reported in the last four months of the year. It is not known what circumstances may contribute to this non-uniform temporal distribution and is an area for further investigation.

Geographic Distribution of Cases

As in 2001, leprosy cases were reported from 28 states in 2002. The table and corresponding density map in Appendix 2 depict HD cases reported in 2002 by state. At 42 cases, California reported almost three times the number of cases as did second place New York with 15 cases. Fully, almost one-third (31.6%) of the 2002 cases were reported from California. Texas, Hawaii, and Louisiana followed New York with 11, 10, and 8 cases respectively. These five states accounted for almost two-thirds (64.7%) of total cases reported. Other than Texas and Louisiana, which have a larger number of indigenous cases, the cases reported from these states are primarity a function of immigration patterns.

Approxi mately 81% (n=108) of the cases reported in 2002 were individuals who were born in 22 foreign countries. While the table in Appendix 3 shows the distribution by country of birth for the cases, the interpretation that most U.S. cases are being "imported" cannot be made unless consideration is given to the relationship between when these individuals entered the U.S. and when they were diagnosed. Of the 23 reported birth countries, the Mexico, (24.1%), the United States (18.8%) and the Philippines (12.8%) represent just over one-half (55.7%) of the reported cases in 2002.

Looking at the 25 U.S. endemic cases reported in 2002, Table 2 and the corresponding map illustrate the distribution of these cases by state of birth.

2002 Registered Leprosy Cases by Month

MONTH	CASES	PERCENT
JAN	17	12.8%
FEB	6	4.5%
MAR	23	17.3%
APR	16	12.0%
MAY	9	6.8%
JUN	11	8.3%
JUL	20	15.0%
AUG	10	7.5%
SEP	8	6.0%
OCT	2	1.5%
NOV	4	3.0%
DEC	7	5.3%
TOTAL	133	100.00%

Table 1

2002 U.S. Native Born Leprosy Cases by State of Birth

CALIFORNIA	3
HAWAII	1
LOUISIANA	8
MASSACHUSETTS	1
MINNESOTA	1
MISSISSIPPI	1
MISSOURI	1
NEW MEXICO	1
NEW YORK	1
TEXAS	8
VERMONT	1
TOTAL	25

Table 2

Historically, there has always been an association between the incidence of Hansen's disease in the United States and geographic location, with a vast majority of the cases being reported from the gulf coastal states. Indeed, in 2002 Texas and Louisiana respectively represented 32% and 24% of native-born leprosy cases, with the combined gulf coastal cases from Louisiana, Texas and Mississippi accounting for 60% of endemic cases.

Distribution of Cases by Race and Ethnicity, Age and Gender

Table 3 summarizes the distribution of the 2002 reported cases by race and ethnicity. These data are also graphically represented in Appendix 4.

2002 Reported Hansen's Disease Cases by Race and Ethnicity		
AMERICAN INDIAN OR ALASKA NATIVE	1	0.8%
ASIAN OR PACIFIC ISLANDER	35	26.3%
BLACK, NOT OF HISPANIC ORIGIN	7	5.3%
HISPANIC, BLACK	6	4.5%
HISPANIC, WHITE	47	35.3%
INDIAN, MIDDLE EASTERNER	17	12.8%
NOT SPECIFIED/UNKNOWN	1	0.8%
WHITE, NOT OF HISPANIC ORIGIN	19	14.3%
TOTAL	133	100.0%

Table 3

Once again, White Hispanics comprised the largest ethnic group representing 35.3% of the total cases, and increasing from the 31.8% of the cases seen in 2001. The ethnic categories that followed are Asian or Pacific Islander (26.3%), White, Not of Hispanic Origin (14.3%), and Indian, Middle Easterner (12.8%). The four groups American Indian or Alaska Native; Black, Not of Hispanic Origin; Hispanic, Black; and Not Specified/Unknown made up the remaining 11.4% of the total cases. As with any race or ethnic classification exercise, these data are more subjective, because they rely on how individuals, and in some cases healthcare workers, perceive race and ethnicity.

Of the 133 cases reported to the registry in 2002, 81 (61%) were male and 52 (39%) were female (see Appendix 5). The age distribution of the sample is summarized in Table 4 and Appendix 7. Age was computed as the age at initial diagnosis.

2002 Reported Leprosy Cases Age Distribution Summary	
MEAN	41.4
STDEV	17.9
MEDIAN	37.6
MINIMUM	13.5
MAXIMUM	85.0
MODE	22.7

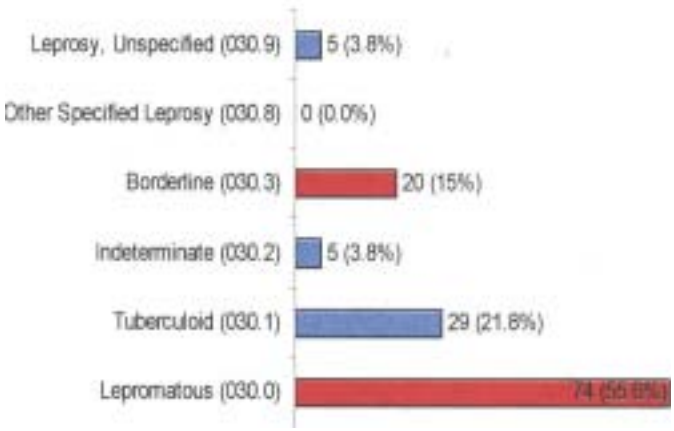
Table 4

The age at diagnosis for the cases reported to the registry in 2002 ranged from 13.5 to 85.0 years with a median age of 37.6 years. This compared to a range of 7.1 to 88.2 years and a median age of 41.8 years reported in 2001. This age distribution is graphically depicted by the boxplot in Appendix 6 which shows the median, upper and lower quartiles and extent of the data beyond the quartiles. While Hansen's disease is predominately diagnosed in older individuals with approximately 50% of the cases reported in individuals between the ages of 30-50 years, the disease is seen in all age groups with the exception of the very young. Some areas for further investigation would be age within gender, race and ethnicity, and severity of the disease (disease classification).

Reported Case Distribution by Disease Classification

The Hansen's disease surveillance form provides for initial classification of the disease into one of six categories which correspond to the universally used ICD-9-CM diagnosis codes for leprosy (030.0-030.3,030.8, and 030.9). The following chart quantifies the cases reported to the registry in 2001 by disease type.

2002 Registered Leprosy Cases by ICD-9-CM Diagnosis Code (n=133)

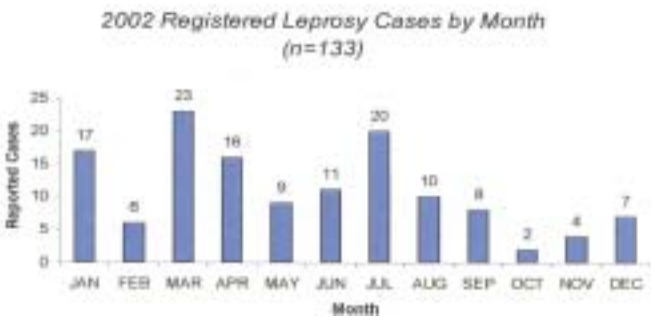


A category of multibacillary cases can be created by combining the borderline and lepromatous classes. Likewise, paucibacillary cases can be identified by grouping tuberculoid and indeterminate categories. For 2002, 94 (70.7%) and 39 (29.3%) of the reported cases are grouped as multibacillary and paucibacillary respectively. The table in Appendix 7 provides the typing of these cases using the Ridley-Jopling classification.

Historical Trend of Hansen's Disease in the United States

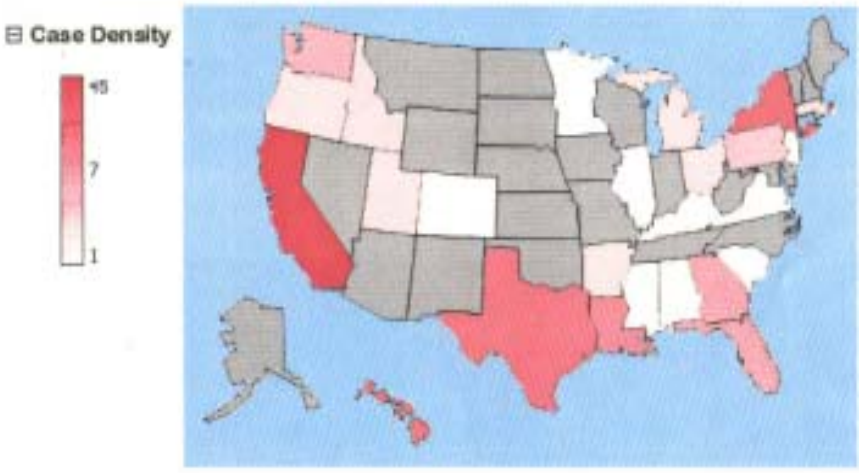
The table and corresponding graph in Appendix 8 shows the number of cases reported to the registry over the past 30 years. With the exception of the period from 1978-1988 when a large number of Indo-Chinese refugees with Hansen's disease entered the country, the number of reported cases has remained relatively constant at approximately 150-200 new cases each year. In the past decade, the number of new cases has fluctuated between 120 and 150. This decrease in reported cases since the early 1990's most likely reflects the decline in leprosy cases reported worldwide. Although the number of endemic cases is stubbornly stable at approximately 25-30 new cases a year, the incidence of Hansen's disease in native-born Americans continues to be a rarity. Unless immigration patterns from areas of the world where leprosy is endemic changes dramatically, the number of new cases seen in this country is expected to be relatively constant in the future.

Appendix 1



Appendix 2

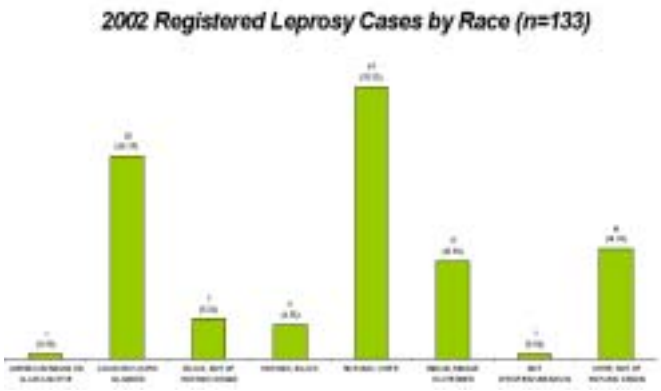
2002 U.S. Hansen's Disease Cases by Reporting State		
STATE	CASES	%
ALABAMA	1	0.8%
ARKANSAS	2	1.5%
CALIFORNIA	42	31.6%
COLORADO	1	0.8%
CONNECTICUT	1	0.8%
DISTRICT OF COLUMBIA	1	0.8%
FLORIDA	7	5.3%
GEORGIA	5	3.8%
HAWAII	10	7.5%
IDAHO	3	2.3%
ILLINOIS	1	0.8%
KENTUCKY	1	0.8%
LOUISIANA	8	6.0%
MASSACHUSETTS	2	1.5%
MICHIGAN	2	1.5%
MINNESOTA	1	0.8%
MISSISSIPPI	1	0.8%
NEW JERSEY	1	0.8%
NEW YORK	15	11.3%
OHIO	2	1.5%
OREGON	2	1.5%
PENNSYLVANIA	3	2.3%
PUERTO RICO	2	1.5%
SOUTH CAROLINA	1	0.8%
TEXAS	11	8.3%
UTAH	2	1.5%
VIRGINIA	1	0.8%
WASHINGTON	4	3.0%
TOTAL	133	100.0%



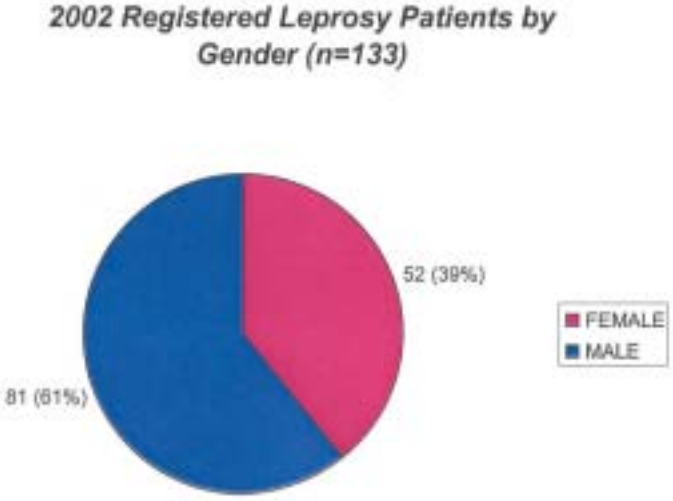
Appendix 3

2002 Reported Hansen's Disease Cases by Country of Birth		
COUNTRY	CASES	%
AMERICAN SAMOA	1	0.8%
BANGLADESH	1	0.8%
BRAZIL	7	5.3%
COSTA RICA	1	0.8%
CUBA	2	1.5%
DOMINICAN REPUBLIC	3	2.3%
ECUADOR	1	0.8%
GUYANA	1	0.8%
INDIA	13	9.8%
JORDAN	1	0.8%
LEBANON	1	0.8%
MEXICO	32	24.1%
MICRONESIA	7	5.3%
NIGERIA	1	0.8%
PAKISTAN	2	1.5%
PHILIPPINES	17	12.8%
PUERTO RICO	4	3.0%
SOMALIA	1	0.8%
ST CHRISTOPHER NEVIS ST KITTS	1	0.8%
TRINIDAD AND TOBAGO	1	0.8%
TRUST TERRITORY	4	3.0%
UNITED STATES	25	18.8%
UNKNOWN	2	1.5%
VIETNAM	4	3.0%
TOTAL	133	100.0%

Appendix 4



Appendix 5



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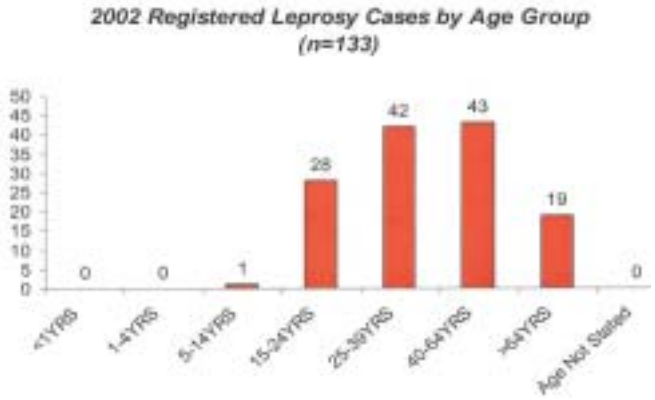
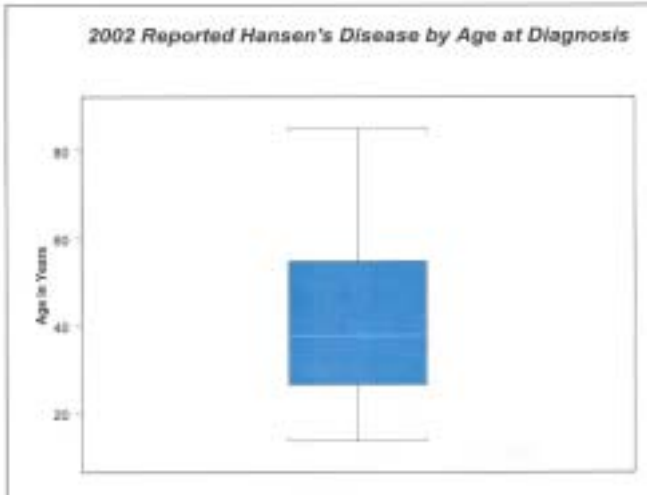


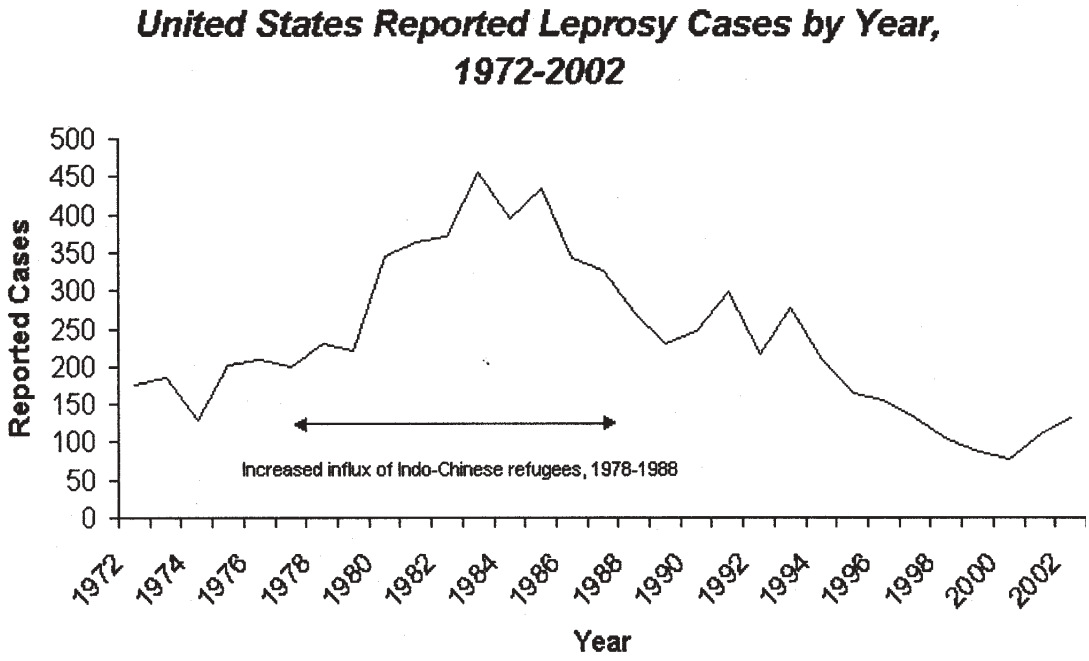


Appendix 7

2002 Hansen's Disease Cases by Ridley-Jopling Classification		
Borderline	15	15.6%
Borderline Lepromatous	13	13.5%
Borderline Tuberculoid	12	12.5%
Indeterminate	4	4.2%
Lepromatous Leprosy	42	43.8%
Tuberculoid	10	10.4%
TOTAL	96	100.0%

Appendix 8

YEAR	CASES
1972	177
1973	186
1974	130
1975	201
1976	208
1977	200
1978	231
1979	220
1980	346
1981	363
1982	371
1983	456
1984	395
1985	434
1986	342
1987	327
1988	270
1989	229
1990	246
1991	299
1992	215
1993	278
1994	208
1995	165
1996	154
1997	132
1998	103
1999	88
2000	78
2001	110
2002	133



In 2002, a total of 133 cases of Hansen's disease were reported in the United States. The number of cases peaked at 456 in 1983, and since 1988 has remained relatively stable.

★★★★★

SOURCES OF HD TREATMENT IN THE UNITED STATES

THE NATIONAL HANSEN'S DISEASE PROGRAMS (NHDP) provides HD care to persons in the United States at 1770 Physicians Park Drive, Baton Rouge, LA 70816 and through the Ambulatory Care Program, which includes the following Outpatient HD Clinics:

NATIONAL AMBULATORY HANSEN'S DISEASE PROGRAM

AREA	FACILITY	ADDRESS	PHYS/NURSE	APPOINTMENT
BOSTON	Lahey Medical Center	41 Mall Rd. Burlington, MA 01805	Samuel Moschella, MD Stephanie Burns, RN	781-744-5670
CALIFORNIA LOS ANGELES	LAC, USCMedical Center Attn: Section of Dermatology Room 8440	1200 North State St. Los Angeles, CA 90033	Thomas Rea, MD Helen Mora, RN	323-226-5240
MARTINEZ	Contra Costa Regional Medical Center Outpatient Clinic	2500 Alhambra Drive Martinez, CA 94553	Sutherland/Saffier, MDs Carol James, RN	925-370-5270 1-800-495-8885 (In state only)
SAN DIEGO	North San Diego Health Center	2440 Grand Avenue San Diego, CA 92109	D. A. Lopez, MD Carmen Rodriguez, RN	858-581-4300
CHICAGO	University of Illinois College of Medicine	Department of Dermatology, (MC 624) 808 S. Wood Street, RM 376 CME Chicago, IL 60612	Carlotta Hill, MD Norma Chelseth, RN	312-996-0734
MIAMI	Jackson Memorial Hospital	Ambulatory Care Center 1611 N.W. 12th Avenue Miami, FL 33136	Anne Burdick, MD Gloria Ingle, RN	305-585-2600
NEW YORK	Bellevue Hospital Center Department of Dermatology Room 17-N-7	462 First Avenue New York, NY 10016	William Levis, MD Aloys Cabrera, RN Louis Iannuzzi, PT, C.Ped	212-562-6096
PHOENIX	Maricopa County Health Dept.	1825 East Roosevelt Street Phoenix, AZ 85006	Ronald Pust, MD Bill Cooper, RN	602-372-6661
PUERTO RICO	University of Puerto Rico Medical School	Department of Dermatology P. O. Box 365067 San Juan, PR 00936-5067	Pablo Almodovar, MD Sonia Santos-Exposito, RN	787-765-7950
SEATTLE	Harborview Medical Center	2 West Clinic - 359930 325 9th Avenue Seattle, WA 98104	James P. Harnisch, MD Rebecca Finch, RN Tom McClure, PT, CH	206-731-5100
TEXAS DALLAS	Texas Dept. of Health	2377 N. Stemmons Freeway, Ste. 5 Dallas, TX 75207-2710	Carolyn Lyde, MD Nancy Bernstein, RN	214-819-2010
HOUSTON	Houston Health & Human Services Dept.	3901 Westheimer, Suite 200 Houston, TX 77027	Terry Williams, MD Doris Gay, RN	713-284-9609
SAN ANTONIO	Texas Center for Infectious Disease	2303 S. E. Military Drive San Antonio, TX 78223	Robert N. Longfield, MD Therese M. Shoffner, RN	210-531-4554
HARLINGEN	South Texas Health Care Center OPCL	1301 Rangerville Road Harlingen, TX 78550	Richard Wing, MD San Juana Thompson, RN	956-423-3420 ext. 351

Other Sources: State of Hawaii Department of Health
3650 Maunalei Ave., Suite 205
Honolulu, HI 96816
Phone: 808-733-9831

Mona Bomgaars, MD
Mike Maruyama, Adm.
Lenette Tam, RN
Fax: 808-733-9836

FOR MORE INFORMATION: Call the NHDP at **1-800-642-2477** or fax: (225) 756-3760
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FACTS ABOUT HANSEN'S DISEASE

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What is (HD)?

Hansen's disease, erroneously associated with biblical leprosy, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr Gerhard Armauer Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without undue difficulty and counteract most of the fears generated by the folklore surrounding this disease.

HD is essentially a disease of the peripheral nerves, but it also affects the skin and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, muscles, bones and testes.

There are both localized and disseminated forms of HD. If left untreated, HD causes nerve damage, which can result in loss of muscle control and crippling of hands and feet. Eye involvement can result in blindness.

Where is HD Found

In 1994 the World Health Organization estimated that there were 2.4 million cases of HD worldwide with 1.7 million cases registered on treatment. The estimates for 1985 were 10 – 12 million and 5.4 million respectively. According to these estimates, in 1994, 70% of those who should be on treatment are now being treated. In 1992 there were 690,000 new cases reported and in 1993, 591,000 cases. There are also an estimated 2 – 3 million cases who have completed treatment but who still have residual disabilities who are not included in the above 1994 totals. The largest numbers of Hansen's disease patients continue to be in Southeast Asia and Central Africa with smaller numbers in South and Central America. The largest number of patients in the Western Hemisphere are in Brazil.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began and still living. The number of cases with active disease and requiring drug treatment is approximately 600. There are 200 – 250 new cases reported to the registry annually with about 175 of these being new cases diagnosed for the first time. The largest number of cases in the US are in California, Texas, Hawaii, Louisiana, Florida, New York, and Puerto Rico. There are still approximately 150 cases at the Gillis W Long Hansen's Disease Center at Carville, LA, the only institution in the US exclusively devoted to Hansen's disease. The center functions as a referral and consulting center with related research and training activities. Most patients in the US are treated under US Public Health Service grants at clinics in major cities or by private physicians. (See inside back page for listing of clinics.)

How Does HD Spread?

While this aspect of the disease remains a medical mystery, the most commonly accepted theory is that it is transmitted by way of the respiratory tract, and abraded skin. The degree of susceptibility of the person, the extent of exposure, and environmental conditions are among factors probably of great importance in transmission. Most specialists agree that 90% or more of the world's population have a natural immunity to the disease. Persons working with HD contract the disease only rarely. Cases of HD which respond satisfactorily to treatment become noninfectious within a short time.

How is HD Treated?

Although the sulfone drugs, introduced at Carville in 1941, continue to be an important weapon against the Hansen bacillus the rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Usually rifampin and sometimes clofazimine or ethionamide are given in addition to dapsone. Treatment rapidly renders the disease noncommunicable by killing nearly all the bacilli and these dead bacilli are then cleared from the body within a variable number of years.

Gillis W Long Center

GET TO KNOW THE FORTY & EIGHT

The Forty & Eight, an honor society of legionnaires created in 1920 and *The Star's* primary funding organization, draws its origin from World War I. Millions of American soldiers in France were transported to the front in narrow French box-cars, called "Voitures," which would only hold 40 men or 8 horses. Remembering the close brotherhood of those box-car days, La Societe des Quarante Hommes et Huit Chevaux (The Society of 40 men and 8 Horses) was formed and local Voitures began organizing as outstanding Legionnaires were invited into membership. Membership is still by invitation only.

Dedicated to the needs of their fellowman, the Forty & Eight raises funds and support not only ***The Star,*** but funds a national nursing scholarship program, various child welfare programs, provides aid to veterans and continues to promote Americanism at both local and national levels.