

# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

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## Carville Monument Dedication

*(Story on page 3)*

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**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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## CARVILLE STAR MONUMENT DEDICATION

by George H. "Doc" Willis, Nationale Directeur, Carville Star

One solemn and dreary night in 1892, the Mississippi River was very quiet except for a lone barge maneuvering its way up the mighty river. There was no sound except the waves lapping against the deserted river bank. On board the large boat were many lost souls—men, women and children—with the dreaded disease called 'Leprosy'. These individuals, abandoned by their families, outcast by their towns and cities, were now all on their own except for each other. The boat veered to the shore and dropped a plank over the side for the passengers to disembark. No one knew where they were—it was dark and scary as these 'diseased' individuals made their way across the levee with only the clothes on their backs and very few possessions. They made their way to an old deserted plantation that was in need of major repairs. This was later to be called the Louisiana Lepers Home. At this time in their lives, 'Leprosy' was believed to be the 'forbidden disease', and if a family member developed the condition, the family believed they had angered God and this was their punishment from God. With these individuals working together, they were able to survive creating a small town known as Carville, Louisiana. Many of them lived to be 80 and 90 years old, and because of the 'disease', they were buried on the grounds of the plantation when they died.

In 1921, a monument was erected with the names of 137 residents of Carville who had passed away since they were "dropped off" that fateful night. This monument was placed in the "front quad" of the compound away from the current cemetery and where very few people had a chance to view. The monument was going to be moved to the existing cemetery. However, when doing research prior to the move, it was discovered there were unmarked graves under the monument and it could not be moved. So in 2007, a duplicate monument was requested and our Forty & Eight responded.

The snow was two (2) feet deep in Michigan, continually snowing in Illinois, raining like cats and dogs in North Carolina, while the sun was shining bright in Carville, Louisiana on 19 February, 2009. There were over one hundred people present—voyageurs, guests, residents of Carville, families of past residents of Carville, and eight distinguished guest speakers including COL Clyde Guidry, Commanding Officer of the National Guard stationed at Carville. As the American flag waved in the spring breeze, a new monument with the 137 names was unveiled by the Guest Speakers at the cemetery to begin the ceremony. George Willis, Master of Ceremonies and Carville Star Directeur Nationale, announced each guest speaker one at a time for their comments on Hansen's Disease, or "Leprosy", as they knew it.

Each speaker spoke on their association with Carville, how it affected their lives and their families' lives, and their association with the publication of "The Star". Our Chef de Chemin de Fer Ted Lang and La Presidente Nationale Sue Houtiekier spoke on La Societe's involvement and the honor our Forty & Eighters and La Femmes have just to be able to support this Hansen's Disease Program with "The Star" publication and the ability of our organizations to be the main contributor to the Hansen's Disease Program.

Mrs. Mary Carville Olivier spoke about her brother, James Carville, an actor, and their life as a family living at Carville, and how their family supported each other as they worked in the local community as Post Master and operators and owners of the General Store. She also applauded the Forty & Eight for their contributions in bringing the new monument to the grave sites of so many deserving residents that once lived at Carville.

Colonel Clyde Guidry, United States National Guard Base Commander, spoke of his association with Carville, the residents, the museum, and the Carville Star Program.

Ms. Elizabeth Schexnyder, NHDP Museum Curator, thanked the Forty & Eight for all their contributions and dedication to preserving the history of "Leprosy" by supporting the museum, and also their contributions for bringing the monument to an area where all visitors will be able to view the history of Carville.

Mr. Jose Ramirez, managing editor of "The Star" publication and an individual having had Han-



sen's Disease, spoke about his life and the stigma associated with this disease and how he, unlike many of the residents at Carville, had the loving support from his family when he was diagnosed with "Leprosy".

Ms. Megan Knapp, Legislative Representative of Lt. Governor Mitch Landrieu, spoke concerning Louisiana's involvement and appreciation for those volunteering and working with Hansen's Disease and Carville Star.

When the ceremony ended, NHDP current residents were invited to the microphone. To the surprise of many, a young man raised his hand to speak. As a resident of Carville, "Jose" spoke on his activities at Carville, his volunteer work at the museum, and his appreciation for the support the Forty & Eight has provided.

Final remarks were made concerning the 'book signing' to be conducted at the Carville Historical Theater by the author and former resident of Carville, Jose Ramirez. His newly released book, "Squint", tells of Hansen's Disease individuals having to 'squint' when looking through slats in fences in order to see what they were not allowed to attend or visit. Elizabeth organized an outstanding reception for the 'book signing' with "King Cake" and beautiful music.

Many stories have been told and books have been written about Carville and Hansen's Disease, but few tell the story like the new monument with 137 names of Carville residents who led the way for a cure for this dreaded disease.

With the addition of the newly dedicated monument, visitors will be able to view 137 names of Carville's first residents, and by visiting the cemetery, they will note 'coke' bottles outlining and decorating the graves and the history that goes with these items. They can also visit the Carville Museum to view memorabilia of past events, artifacts, and the history of how these courageous individuals lived, survived, how they were treated, and how they enjoyed life at Carville.

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## **Recognition of Advocates** by José Ramirez, Jr.

Every two years, The Leprosy Mission International (TLMI) based in London, England accepts nominations for the Wellesley Bailey Award. The award recognizes the memory of Wellesley Bailey who was a pioneer in doing missionary work on behalf of persons affected by leprosy. The award also honors two individuals, one man and one woman, who have made major contributions in changing the negative image of leprosy and assisted in positively impacting the lives of others affected by leprosy. For 2009, the honorees are Mr. K.V. Shetty of India and Ms. Parwati Oli of Nepal. Mr. Shetty and Ms. Oli were honored in Ontario, Canada recently.

Mr. Shetty, age 77, was diagnosed with Hansen's disease at age 10 in a community that believed that "leprosy was a cause of an angry God and that the illness was incurable and hereditary." In spite of painful stigma, progressive disabilities, and rejection by neighbors, Mr. Shetty secured a formal education, worked as a teacher, became a social worker, advocated with persons affected by leprosy who were homeless due to their illness, made hundreds of presentations dispelling myths about the disease, and wrote three books about his experience.

Ms. Parwati, age 35, was diagnosed at age 9 and experienced much rejection from her community of origin. She experienced first-hand how women are denied their identity due to Hansen's disease and decided at a young age to do something on behalf of women affected by leprosy. Ms. Oli received her degree in nursing and works at the same hospital where she was treated as a young girl. In 2003, she was invited to the First International Workshop for Women Affected by Leprosy in Seneca Falls, New York. In 2008 she co-signed the document "Global Appeal to Eliminate Stigma." Currently, Ms. Oli serves as Vice-President of IDEA Nepal for Advocacy on Women's Issues.

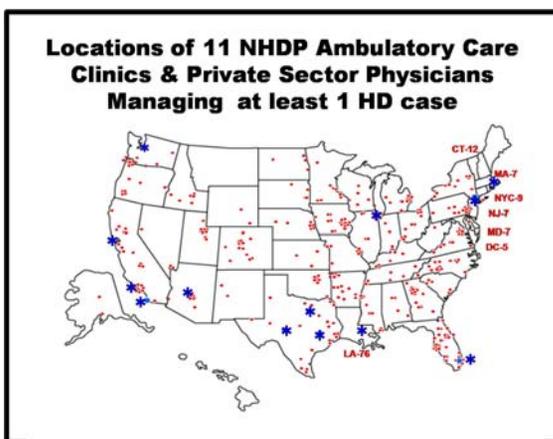
The Star is proud to recognize these wonderful advocates.

## The Need for Hansen's Disease (HD) Awareness in the U.S.

**James L Krahenbuhl, Ph.D.**  
Director, National Hansen's Disease Programs,  
Bureau of Primary Health Care  
Health Resources Services Administration  
U.S. Dept. of Health and Human Services

The National Hansen's Disease Programs (NHDP) records approximately 150 new cases of HD in the U.S. each year (2005-161, 2006-137, 2007-157, 2008-150). Approximately 6,500 persons with HD are living in the U.S. today and ~3,500 cases are being managed in 11 NHDP ambulatory care program (ACP) clinics or by private practice physicians with consultation and services provided by the NHDP ([www.hrsa.gov/hansens](http://www.hrsa.gov/hansens)).

The 11 ACP clinics are strategically located around the country in major cities and manage approximately 3,000 cases. These clinics were funded under contract with the NHDP beginning in 1982 following the closure of local U.S. Public Health Service (PHS) hospitals. Each ACP clinic is staffed by at least a physician (leprologist) and nurse with years of expertise in managing HD cases. Some of the clinics also include access to physical and occupational therapy and social services.



Another 550 or so cases are being managed by 500 private sector physicians scattered throughout the country (see map). Within the ~ 150 new cases of HD seen each year there are ~30 patients who live almost exclusively in southern Louisiana and the Gulf Coast of Texas and their infection may be linked to the high prevalence (15-20% in some areas) of infection with *Mycobacterium leprae* in nine banded armadillos. Scientists demand a high burden of proof to make this connection and researchers from the NHDP are developing a "DNA fingerprint" assay that may link armadillo derived strains of *M. leprae* with those isolated from HD patients.

The number of new cases each year remains relatively constant. However, what has raised the concern of the NHDP in recent years is the advanced stage of disease that is being seen due to late and misdiagnosis. These people are often young individuals with nerve involvement and damage, the hallmarks of HD, already present. They will have to be managed for the rest of their lives. Multiple drug therapy is extremely effective and early diagnosis and treatment is the best way to prevent nerve damage or disability. There are a number of reasons for this delay in diagnosis. HD is a slowly developing chronic disease; 3 – 10 years may elapse before clinical symptoms appear. Many individuals with HD are often uninsured or under-insured and do not routinely seek medical care for slowly evolving skin problems. But when they finally do seek medical care, often at a community health clinic or emergency room, the general lack of awareness of HD in the U.S. by private sector physicians results in misdiagnosis and, consequently, ineffective treatment. It is not unusual to hear that patients have seen two or three different doctors over several years before the diagnosis of HD was made.

In 2007 the NHDP launched a new training initiative; seminars aimed at "Increasing the Awareness of HD (leprosy) in the U.S.". Compacted into four hours these seminars are aimed at private sector physicians from a variety of specialties (dermatology, infectious diseases, family medicine, emergency room, etc.) as well as nurses. The venues for these seminars have been chosen where a concentration of new cases has been reported (NW Arkansas, Boston, Atlanta) and the NIH Clinical Center.

Given the world-wide mobility of people these seminars are aimed at raising the index of suspicion that HD can present in people from endemic areas and patients residing in the Gulf Coast. Physicians and nurses are taught that there is no diagnostic test to detect pre-clinical disease. However, a presumptive diagnosis can be made based on history and examination for the cardinal signs of HD; especially chronic skin lesions with sensory loss or, in more advanced cases, enlarged peripheral nerves, loss of eyebrows, swollen, nodular ears or a history of painless wounds or burns. Attendees are instructed to take a skin biopsy from the edge of the lesion and send it to NHDP for confirmation of their presumptive diagnosis and staging of

the disease for the appropriate treatment regimen. With the other services the NHDP provides (free anti HD drugs, consultations with NHDP physicians, therapists and social workers) these patients can be readily managed by the local physician. In the event that the disease cannot be managed (reactions unresponsive to treatment, requirement for advance wound care or reconstructive surgery) the patients can be referred to NHDP to obtain the appropriate treatment.

Increasing the awareness of HD (leprosy) in the U.S. will remain an important proactive part of the NHDP mission. An exhibit and a symposium have been presented at national medical meetings (American Academy of Dermatology, American Society of Tropical Medicine) and more are planned. More seminars are planned for major medical centers. A web--based course is being developed and plans are underway to bring HD training to the community health centers across the U.S.. Early diagnosis and effective treatment is the goal.

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## **Stigma and Discrimination: An Editorial** by José Ramirez, Jr.

In April 2009, the South-East Asia Regional Office of the World Health Organization (WHO) hosted a meeting in New Delhi, India, to develop 2011-2015 strategies for reducing the disease burden due to leprosy. Representatives from 44 different countries and 70 experts were invited to participate in this important meeting. I was one of the four individuals invited by WHO affected by leprosy; others were Dr. P.K. Gopal, Nervis Mary, and Zilda Borges; I was also one of nine who made a presentation during the three day meeting.

At this unique meeting, WHO took some giant steps to address issues that go beyond the general physical treatment of Hansen's disease (HD). In the world of leprosy, HD continues to be less and less in the number of new cases; however, the level of discrimination and stigma against persons affected by leprosy has not declined along with the downward spiral of new cases.

Stigma is a derivative of a Greek word meaning "scar" and it has become an act of labeling, rejection, and unexplained fear of a person. Stigma has existed for over 40 centuries and spread out like an epidemic by approximately 100 generations of families who have been exposed to the myths about leprosy. Stigma has branded persons affected by leprosy with an image that projects negative images and sin. Stigma has been imposed upon persons affected by leprosy by researchers who describe painful experiences of depression, stress, suicide ideation, and loss of identity as "self stigma," further labeling those visited by the HD bacillus.

In order to overcome stigma, the participants at the WHO meeting were encouraged to cease contributing seeds that feed stigma. These seeds include: language – labels in religion, research, and treatment; partnerships – delete exclusionary practices and add inclusionary ones; and counseling – make available trained professionals who can act as first responders to the emotional needs of those affected by leprosy.

The meeting ended with an endorsement by the attendees of not only the plan to collaboratively address the medical treatment of HD, but more importantly, the inclusion of persons affected by leprosy in the development and implementation of policy – a giant step towards the lessening of stigma and discrimination.

The particular outcome is another example to the world that persons affected by leprosy can and must continue to be part of the infrastructure to address leprosy-related issues.

Advocates of the past, in particular, Bernard Punikia'a from Kalaupapa Settlement in Hawaii who died on February 25, 2009, would be very proud of the four who participated in the WHO meeting. Bernard's "Quest for Dignity" is still alive.

**Don't Fence Me In: *The Holes in the Fence***  
**Elizabeth Schexnyder, Curator, National Hansen's Disease Museum**

“Tell us about the “hole in the fence!” That is a phrase I can expect to hear on a regular basis from museum visitors. Years of research and conversations with former patients have taught me that there was more than one “hole in the fence”. There was a “hole” in the backside of the 400+ acres of the Carville hospital near Lake Johansen. That hole was for spending days on the Mississippi River; young patients hid boats and paddled to sandbar islands for fishing or picnicking. There was another “hole” in the corner of the patients’ golf course. The golf course “hole” was convenient to a getaway car on River Road and far from the guardhouse. Mary Ruth Daigle said that she and Wasey paid a cafeteria employee to “meet us at the hole” for trips to Baton Rouge to see LSU play football. This was obviously a regular event as Mary and Wasey were season ticket holders!

After the 1940s brought miracle drugs and most patients’ stay shortened from “life” to a few years, another hole appeared. This one was near House 29, more convenient, but closer to the guardhouse. A pass was still required to leave the hospital grounds, but the consequences of sneaking out diminished. The House 29 “hole” was a handy exit for those who did not complete the required paperwork. A former patient from the 1950s said, “There were times when I forgot to fill out the pass, so I left through the hole. Once my blouse snagged on the fence, and there was a hospital employee driving down River Road, so I waved, and they waved back!” Seems everyone knew about the hole and its function. Today, there is a metal grate blocking the House 29 hole, but it is still visible.

In the early days, “absconding” through the hole earned the offender 30 days in the Carville jail. The federal government built a jail on the hospital grounds in 1926 after one patient murdered another patient. The suspect had to stay in quarantine, so in essence a “jail within a jail” was constructed. I heard a funny story about Carville’s jail. When hospital guards made their rounds, which included the River Road around the hospital’s perimeter, they often found bicycles, but no riders. Apparently, ingenious anglers found a way to get their bikes through the hole as well as their bodies. Well the guards would look around for the angler first, but if they could not find him/her, off the bicycle went to jail—for 30 days! The PHS demolished the jail in 1956, the year before Hansen’s disease disappeared from Louisiana’s roster of quarantinable illnesses.

Traffic through the hole worked both ways. A local woman, who was a young girl when her mother was treated here in the 1940s, told me she sneaked *into* the hospital through the hole. At the time, she was too young to “legally” visit. She even has photographic evidence. Stanley Stein tells us in *Alone No Longer*, that hard liquor came in through the hole (it was forbidden) along with “ladies of the night”.

People went through the hole in the fence to get married, to talk a spouse out of divorce, to go dancing, to rendezvous with a lover, to join the armed forces, or just to get back a feeling of control and “normalcy”. Some patients who left through the hole and never came back, even though to leave the grounds against hospital advice meant a warrant for arrest.

The “holes in the fence” have symbolically mended, as quarantine became a policy of a past era. When I share these stories with museum visitors, some poignant and sad, others humorous, I end by asking a person “would you have gone through that hole?” To a person the answer is “yes!”



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**FOR IMMEDIATE RELEASE**

**April 30, 2009**

### **National Guard brings new life to Gillis W. Long Center**

**By Sgt. Beyonka D. Joseph**  
**Louisiana National Guard State Public Affairs Representative**

CARVILLE, La. – With so much history and diversity, the Gillis W. Long Center has continued to be a local legacy for the community of Carville, La.

In 1999, faced with a dwindling patient population, the United States Department of Health and Human Services turned what was originally the sugar cane Indian Camp Plantation back over to the State of Louisiana in legislation that has been called “The Baker Bill.” It was named in honor of the bill’s author and staunch supporter of the facility and its programs, Congressman Richard Baker.

The State of Louisiana Military Department gained oversight of the property in April of 1999, beginning a new era for Carville. At that time, many of the patients who were treated at the Hansen’s disease Center were given the choices to return to their own communities with a stipend, continue their care at another hospital or remain at Carville.

More than 40 patients elected to remain on site to continue to receive medical care and housing. These residents are still very much a large part and the heart of this facility and have helped to build a museum of the facility’s history.

In April of 1999, the Youth Challenge Program opened its doors at GWLC, making Louisiana the only state with three Youth Challenge Programs. They are located at Camp Beauregard in Pineville, La., Camp Minden in Minden, La., and at the Gillis W. Long Center in Carville, La.

The Louisiana Youth Challenge Program is a multifaceted program that aims to help at-risk adolescents achieve their education and become productive and responsible members of society. The program sponsored and managed by the Louisiana National Guard, is a nonprofit organization funded 60 percent by the federal government and 40 percent by the state.

The Youth Challenge Program has continued to excel throughout its duration and has graduated close to 200 cadets biannually for a total of more than 3200 cadets. This structured program has helped combat the state’s high school dropout rate tremendously while improving Louisiana’s leading race to take back youths.

The Youth Challenge Program consists of two phases where cadets are taught eight core components: life coping skills, academic excellence, job skills, responsible citizenship, leadership and follower-ship, health and hygiene, physical fitness, and service to community. Phase one, which is a 22 week residential alternative military like school, offers youths an opportunity

to work on their education and life skills in a structured and disciplined environment.

The second phase is a 12-month post-residential phase that consists of case managers and community mentors assisting cadets with their future life goals and skills obtained through the residential phase. In this phase, cadets are monitored as they return to their communities to continue their education or begin employment.

Upon successful completion of YCP, many cadets continue their training at the Louisiana National Guard Job Challenge Program, which is also located at GWLC. JCP is a nationally accredited 90 day skill training program and pre-GED school that enables a select group of cadets who have graduated from the Youth Challenge Program an opportunity to participate in training which helps them to enter into the Louisiana workforce.

The program offers certifications in various trades such as: heavy equipment, welding, culinary arts, carpentry, landscape and turf management, construction technology, arboriculture, emergency medical technician and firefighter I and II. Each course varies in size and length based upon industry support. The curriculum combines classroom work, community service, skill training, and individual/team activities into one unique experience.

Since its inception in 1999, JCP has graduated more than 1400 students and continues to provide young people with support and an opportunity for positive growth.

In 2002, seeking a way to educate emergency personnel after 9/11, the Southern Anti-Terrorism Training Academy and the Louisiana State University also moved its Law Enforcement Training Program to the GWLC to begin training police officers and first responders in anti-terror education and tactics.

Later in 2003, the Louisiana Department of Health and Hospitals began relocating some of their Bio-terrorism Unit staff to GWLC. Currently they have plans to remodel their building into a state of the art bio-terrorism training facility.

Recently, the Gillis W. Long Center also became home to the newest chapter of the first tee program, The First Tee of Carville. The mission of the program is to impact the lives of young people by providing learning facilities and educa-

tional programs that promote character development and life-enhancing values through the game of golf.

“If it wasn’t for these programs that we have here at the Gillis W. Long Center, there would have never been a need or purpose for this facility,” said Col. Clyde J. Guidry, post commander of the GWLC.

So much history and work lives here at the Gillis W. Long Center. In 1994, at the Carville Centennial Celebration, someone threw out the question, “Will Carville have a second century of glory?” You may ask that to the hundreds of youths who have passed through these gates with changed life paths and goals, or ask the men and women who train here everyday in hopes to keep our homeland safe. We think the answer would be a resounding, “Yes!”

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## From The Leprosy Museum in Bergen, Norway

The Leprosy Museum in Bergen was established in the early 1970s, in the old St. Jørgens Hospital, which was a leprosy hospital from 1411-1946. The main ambition was in the 70s “to show that leprosy had been a serious health problem in some parts of Norway in the 19<sup>th</sup> century, and how the cooperation between public health authorities and medical experts contributed to the eradication of the disease”. In other words, the museum was supposed to be a traditional medical museum, highlighting the scientific breakthroughs within leprosy research which took place in Norway, and in particular Armauer Hansens discovery of the leprosy bacillus in 1873.

Even though many Norwegians are well aware of the fame of Hansen, and often feel flattered by the interest that tourists and visiting experts display concerning both Hansen and the museum, the museum was actually given less priority by our museum authorities. In the late 1990s, before the museum got its first professional museum employee, the exhibitions were outdated, and the museum labelled in guidebooks as an “obscure and unusual sight”.

Since then we have worked on the museum narratives to make ourselves understood. In 2001, The Bergen Leprosy Archives were included in the UNESCO programme “Memory of the World”, and in 2003 the Norwegian prime minister could re-open the museum and its new exhibitions. Now, the famous medical research still had its place, but more attention was given to the people and individuals who once lived at the hospital. We did not want to present them only as “patients” or “cases of leprosy”, but as individuals and part of the hospital community.

Visitors at the museum are no longer introduced to grouped case studies with medical comments, but to 12 rooms with one person in each, with different contemporary written sources such as short biographies, letters, hospital reports, patient records and even a religious poem written by one of the hospital’s patients in 1835.

It is all about identity, and the museum approaches this issue in different ways. In another room we made a large black plate with the 8231 names, printed in white. The plate looks almost grey from a distance, and visitors are often very touched when they discover that it contains the names from the Norwegian Leprosy Registry. I am quite sure that this is because such memorial plates represent such a universal language, and that this one states something very specific about what leprosy has represented in small Norwegian societies. It also expresses a view on leprosy as a phenomenon quite different from those found in medical museums or among traditional historians of medicine: leprosy is first of all a social issue, and the museum has an obligation to not only honour medical men, but to stress the social aspects. That is exactly what this plate does. Today’s Norwegian visitors, who tend to know very little about the disease, often find the names of their family farms on this plate, or they discover that leprosy was common in their region a generation or two ago.

Last year, a family came to the museum showing copies from the local archives, documenting the life of one of their ancestors who had been in one of the Norwegian state asylums for many years. The family had now reconstructed her biography piece by piece, and they were very interested in what the museum guide could tell them about hospital life in the 19<sup>th</sup> century. But when they found her name on the plate, several of them started to cry. One thing was to reconstruct a tragedy within their own family, another thing, obviously, to be confronted with the fact that she was part of such a large community.

Telling and exhibiting the history of leprosy takes many forms, and I am not sure that memorial plates is the only right way to go. Perhaps we shouldn’t re-victimise people. However, I see that our plate works as an eye-opener in this particular setting, and that many visitors have touching and thought-provoking moments when they discover their own family names in the exhibition at the Leprosy Museum.

Sigurd Sandmo, curator

## “A Farewell” by Valerie Monson

Many years ago when Bernard and I were doing an interview, the subject of death came up. “When I die, I don’t want people crying,” he said. Then he paused, got that innocent Bernard grin and added “Well, maybe a little.”

So you have his permission.

We are here to celebrate the life of Bernard Ka`owakaokalani Punikai`a. His Hawaiian name means “bright light in the sky.” I think we would all agree that he lived up to his name.

Over the years, I came to think of Bernard as part Martin Luther King, Jr., and part Gabby Pahinui – and a little bit of Oscar from the Odd Couple. The Martin Luther King side of Bernard drew most of us in this sanctuary to him. Bernard had a brilliant mind, a love of reading, great vision and the charisma to rally people around him. He was remarkably eloquent whether in speeches he wrote, songs he composed or just every day speaking. He described Father Damien as “my north star” – one bright light in the sky talking about another – and he coined the phrase, “Quest for Dignity,” which would become a cry of empowerment around the world. Most of us know about Bernard’s impact here at Kalaupapa and in Hawaii, but I’m not sure people realize what a difference he made globally where he spoke at international conferences as well as in small remote villages very much like Kalaupapa. He gave a keynote address at the United Nations, he received an award in India, and his name was recently part of discussions about human rights in Geneva. Upon news of his death, we received condolences from Japan, Korea, Africa, Brazil, India, the US Mainland and China. One friend simply wrote: “We are all shattered.”

That was the Martin Luther King side. And then there was the Gabby side where Bernard could charm complete strangers with his music. About 10 years ago, I was coming back from China with Bernard and two women from Kalaupapa – Cathrine Puahala and Elaine Remigio. We had a long layover in the Taipei airport that we were all dreading until Bernard pulled out his autoharp – he always took his autoharp when he traveled – and he just put on an impromptu concert right there in the terminal. Pilots stopped, flight attendants stopped, everyone stopped in that part of the airport to listen to Bernard. The long layover disappeared in minutes and, as we boarded our next plane, we were treated like celebrities.

When we got back to Honolulu, we were heading to the long line in customs when an agent saw us and called out “Welcome Home, Mr. Punikai`a.”

I asked Bernard “Who’s that?” and Bernard replied, “I don’t know.” The man took us and led us past the lines to an agent who was open. We were out of the airport in 10 minutes – all because we were with Mr. Punikai`a.

That was Bernard. Wherever you went with him, people recognized him. They called out “Aloha, Bernard.” “Hello, Mr. Punikai`a.” Whether you were at a restaurant, just walking along the street or in the halls of the State Capitol, everyone knew Bernard. He was the champion of the ordinary guy, a hero of underdogs everywhere.

I think part of that appeal came about because Bernard was a man of principle who never compromised. It’s easy to espouse your principles and your philosophies when life is comfortable, when you have a home and family, a steady job and money. The real test of your principles comes when you must sacrifice for them, when you must stick yourself out there, when you must stand alone. After Hale Mohalu was razed, Bernard made sure everyone was safe at Leahi or back at Kalaupapa, but he knew he could not do the same. He knew if he went back to Kalaupapa, the state would think they had won. He knew he had to stay in Honolulu so state officials and everyone else would continue to see him around town and know that he was not finished. The problem was that Bernard’s Honolulu home, Hale Mohalu, had been destroyed, leaving him homeless. So he lived in his car, parking overnight where people would let him, cleaning up at friends’ houses, staying at the Y if he had some money.

For Bernard, Hale Mohalu did not end with the bulldozers. He was worried about the housing needs of all seniors with limited incomes – not just people affected by leprosy -- and so he and others formed the Coalition for Specialized Housing. About 10 years later, ground was broken in Pearl City for the senior housing complex that Bernard helped to design. Anyone who once had leprosy gets priority at an apartment, if they so choose. The completion of the new Hale Mohalu was really one of Bernard’s crowning achievements.

Bernard also had the vision 13 years ago to realize that the people of Kalaupapa would need support from family members and friends when they got older and their numbers got smaller. He was the force behind Ka 'Ohana O Kalaupapa, which has become an organization, looked to by other communities like Kalaupapa in the rest of the world who are also facing an aging population and smaller numbers.

Last month, Bernard was laid to rest at Kalaupapa next to Kenso Seki, a man who was sent to Kalaupapa in 1928 and who walked in Damien's footsteps – Kenso was a man who Bernard loved and greatly admired. When Bernard was young, shy – if you can believe that – and missing his mother terribly, he would go up to Kenso's room at the new Baldwin Home where Kenso would look after him. Bernard's admiration of Kenso never wavered. When Kenso died in 1998, I interviewed Bernard for Kenso's obituary. These were Bernard's concluding remarks about Kenso:

"I can see Kenso now," said Bernard, "standing before God, and God is saying to him, 'You know, Kenso, you did good. Thank you.' Yes, I can imagine God thanking Kenso for all he did for Kalaupapa."

I can imagine something similar happened five weeks ago on Ash Wednesday when Bernard made his final journey. I can imagine that God was waiting for him and called out "Welcome Home, Mr. Punikai'a." And then Bernard would have stood before God who might have said "You know, Bernard, you did well Thank you." Yes, I can imagine God thanking Bernard for all that he did for Kalaupapa and for so many people around the world.

Mahalo, Bernard, from all of us, for your friendship, your wisdom, your values, your music and your sense of humor. You will always be our bright light in the sky.

\*\*\*\*\*

## **Joey G. Remembered** by E. Schexnyder, Curator, National Hansen's Disease Museum

Recently during a group tour, a woman strode up to me and placed a folder in my hands— "I think you'll find this interesting" she said. Inside were 10 photographs of Josefina Guerrero. Very interesting indeed. Joey, a native of the Philippines, joined the underground resistance during World War II. When the Japanese took over the island, she recorded and smuggled-out secret information to aid the Americans. Because she had leprosy, the Japanese soldiers were not eager to search her. Her gutsy work identifying mined beaches saved hundreds of American lives. Joey was awarded the Medal of Freedom by the US Government. In 1948, in thanks for her heroism, she was transported to Carville for treatment.

"Boots" McArdle (nee Henrietta Ware) told me how she met "Joey" in 1948. Boots grew up in Mississippi. She had a Catholic education that eventually took her to Loyola in New Orleans; Boots was 20 years old when she met Rev. Mother LaPierre of The Religious of the Sacred Heart. The Rev. Mother asked Boots to drive her to Carville to visit a young patient from the Philippines. Boots' first impression of Joey was of a well-educated and friendly woman who spoke excellent English.

As she reminisced over the snapshots, Boots lingered over a Carville Mardi Gras scene and said the choice of jester costume that Joey wears suited her personality perfectly. "She was lively and full of confidence. I marveled that Joey still maintained optimism and spunk even though her husband and family disowned her when she was diagnosed with HD".

When Boots attended LSU graduate school in Baton Rouge, she continued to visit Joey. Their friendship remained steady until Joey married a fellow patient in 1957 and moved to California. Before she left, Joey gave Boots a pair of sugar tongs shaped like a wishbone, a family heirloom Boots had admired. At the junction, where the two prongs join, are the three moral monkeys (see, hear, & speak no evil). Boots still treasures the gift. She would love to know what became of Joey.

So would we! The STARS mentioned Joey in the Nov-Dec 1964 of "News of Former Patients" section. Joey, then living in San Francisco with her husband, was granted "permanent residence" in the US. In the same year, 1964, the Reader's Digest published "Joey's Quiet War", an account of her WWII heroics. However, the last mention of Joey found in the STAR archives dates to Nov-Dec 1967. The title rings out "Joey Gains Citizenship after Long Struggle". The article recalls her journey to achieve US citizenship and her trials and tribulations with HD, for which, ironically, she was denied citizenship for many years. The US Congress finally removed that barrier in September 1961. A postscript note in the 1967 article quotes from a letter sent by Joey; she is doing fine, working on the campus of San Francisco State College after completing a degree in English. She hopes to become an elementary school teacher.

You can bet that she did. What a life! What a legacy: war hero, HD patient, advocate, friend, wife, and finally teacher.

## Two Miracles at Carville by Ymelda Rivera Beauchamp

When José Ramirez, Publishing Editor of the Star asked me to write about the two miracles at Carville, the request prompted a startling and unsettling realization...was there something about Carville I did not know? "two miracles," Was he kidding? In all my years at the hospital I witnessed dozens, perhaps hundreds of small miracles day to day ...medical, spiritual and personal. I saw people metamorphose from newly diagnosed to a wholesome healthy stage. I saw residents leaving Carville to live a normal life in their communities. Which of these miracles was the Editor referring to? So here began my search for those two nebulous miracles, and along with that the humbling acceptance of my unequivocal ignorance.

I asked several people who offered no answers but quickly apologized for their lack of information. After a couple of days my search led me to some forgotten memorabilia from Carville in my own home. Under no specific author, this is what I found:

### *MIRACLE AT CARVILLE*

"Nestled under a clump of trees, is the Carville cemetery, its graves giving mute testimony to the lives and deaths of patients who never went home because the Miracle of Carville was after their time.

The road to the discovery of the miracle cure of leprosy was a long and arduous one. By 1921 Chaulmoogra oil, a rather vile-tasting, largely ineffective product of the hydnocarpus tree was the treatment of choice. The disease was still painful and often resulted in disabilities, but the greatest pain was due to the stigma and discrimination.

In the spring of 1941, Carville had evolved into a major research institution. On March 10 of that same year, The Miracle of Carville occurred quietly when six volunteer patients received injections of the sulfone drug Promin. The first volunteers improved slowly but dramatically after treatment. Early cases recovered within six months and advanced cases got better in two to three years. Soon other drugs were added. Carville unveiled Diasone in 1943 and for the first time in history, Hansen's disease patients began to get well and discharged in large numbers from Carville.

The sulfone drugs which were unveiled in Carville and introduced by Dr. G. H. Faget revolutionized treatment of leprosy all over the world. **Leproy was finally under control. Thus, the First Miracle at Carville...**

But the miracle that occurred in the lives of those first patients has never been duplicated. Betty Parker from New Orleans was diagnosed as having leprosy in 1928. She was admitted to Carville where she met Harry Martin, fell in love and ran away from the hospital together. In 1939 Betty and her husband Harry Martin voluntarily returned to Carville. Years later, Dr. Faget developed Promin, Betty and Harry were the first to volunteer for it. In a couple of months their tests began to report negative and after twelve consecutive months of negative results Betty and Harry were pronounced cured and discharged. In 1950, Doubleday published Betty's autobiography "Miracle at Carville."

### *SECOND MIRACLE AT CARVILLE*

Ymelda Beauchamp - contribution by Anwei Law

The Second Miracle happened in 1999 and this event came as a result of a campaign to eliminate stigma. IDEA (International Association for Integration of Dignity and Economic Advancement) designated March 11 as the International Day of Dignity and Respect to be celebrated annually as means to focus on the dignity inherent in every human being.

The first International Day of Dignity and Respect was organized in the US at the Gillis W. Long Hansen's Disease Center in Carville, La. March 11, 1999. A historic march led by IDEA members took place on this day with a demonstration by residents, former residents, workers and community members who marched from the Recreation Building to the Center's Cemetery. The demonstration was in protest to the government's proposed plans to relocate the residents of Carville from the place they had made into their home.

Over the years, March 11 has evolved into a day to focus on issues faced by people affected by leprosy and the widespread human rights violations throughout history all around the world. The principal objective is to get rid of the stigma and discrimination that continues to deny individuals their right to lead productive lives with dignity in their homes and communities throughout the world. Two miracles 58 years apart, one cannot exist without the other, one must not exist without the other. Therefore, these two ominous events remain equally indelible in the life of Carville.

***March 11, an International Day of Dignity and Respect***

*And here you have it Mr. Editor, "The two Miracles at Carville." Thank you for the assignment..... I learned much. Ymelda*

## Terminology Guidelines

### Terminology Guidelines\*

#### Language Forms Options

*“We will call each of us by our own names with respect and dignity.  
We do not accept that we be called by the name of the disease  
or ill people after we have been cured.”*

#### IDEA Mozambique Declaration

Every culture has language that promotes dignity and language that is hurtful. To change the traditional social image of leprosy, it is important to use language that promotes dignity, recognizes a person as an individual separate from the disease, and focuses on ability rather than disability.

A person should be referred to by their name whenever possible. If it is relevant to indicate that they have had leprosy, use the phrase “person affected by leprosy” or a “person challenged by leprosy,” or “person who has experienced leprosy,” placing word “person” first. In countries where the term “Hansen’s disease” is preferred, use the phrase “person affected by Hansen’s disease.” Abbreviations like “PAL” or “LAP” should not be used since they become another label.

Never use derogatory words such as “leper” or words that define a person by their disease like “Hansenite.”

Do not use labels such as “victim” or “sufferer” which suggest helplessness.

Avoid words or images that promote pity or guilt.

Do not use the words “crippled,” “deformed,” “deformity.” Instead, use the word disability and use specific terms that describe a person’s condition in neutral, inoffensive language.

The terms “leprosy patient” and “Hansen’s disease patient” should only be used in clinical settings, not to describe individuals once they are cured. Similarly, it is inaccurate and inappropriate to continue to refer to someone as a “former patient” or “ex-patient” once they are cured.

Always emphasize people, not labels.

*“We refuse to allow others to define ourselves, our humanity, by a disease.”*

Bernard K. Punikai`a, Hawaii, IDEA’s President for Advocacy (1997-2007)

\*Developed by IDEA, [www.idealeprosydignity.org](http://www.idealeprosydignity.org)

## **HANSEN'S DISEASE CLINICS**

### **BOSTON HD CLINIC**

Lahey Medical Center  
41 Mall Road  
Burlington, MA 01805  
PH: (781) 744-5670  
Fax: (781) 744-5687  
Primary Physician - Dr. Samuel Moschella  
*email: samuel.l.moschella@lahey.org*  
Public Health Nurse - Ms. Stephanie Burns, R.N.,  
D.N.C.  
*email: stephanie.a.burns@lahey.org*

### **CHICAGO HD CLINIC**

University of Illinois  
College of Medicine at Chicago  
Dept. of Dermatology, (MC 624)  
808 S. Wood, RM 376 CME  
Chicago, IL 60612  
PH: (312) 996-0734  
Fax: (312) 355-0870  
Primary Physician - Dr. Carlotta Hill  
*email: chhill@uic.edu*  
Public Health Nurse -  
*email:*

### **LOS ANGELES HD CLINIC**

LAC+USC Medical Center  
Attn: Section of Dermatology  
Room 8440  
1200 North State Street  
Los Angeles, CA 90033  
PH: (323) 226-5240  
Fax: (323) 226-2654

Primary Physician - Dr. Thomas Rea  
*email: rea@hsc.usc.edu*  
Public Health Nurse - Ms. Helen Mora, R.N.  
*email: hmora@lacusc.org*  
Occupational Therapist - Rob Jerskey  
*email: robjerskey@yahoo.com*

### **MARTINEZ HD CLINIC**

Contra Costa Regional Medical Center  
Outpatient Specialty Clinic  
2500 Alhambra Avenue  
Martinez, CA 94553  
PH: (925) 313-6726  
Fax: (925) 370-5279  
Primary Physician - Drs. Sutherland/Saffier  
Dr. Sonia Sutherland/*email: sesutherland151@pol.net*  
Dr. Ken Saffier/*email: ksaffier@yahoo.com*  
Public Health Nurse - Ms. Elise Judy, R.N.  
*email: ejudy@hsd.co.contra-costa.ca.us*

Community Health Worker - Maria Soto Phone:  
(925) 370-5868

### **MIAMI HD CLINIC**

Jackson Memorial Hospital  
1611 N.W. 12<sup>th</sup> Avenue  
ACC East - 2<sup>nd</sup> Floor  
Dermatology - Hansen's Clinic  
Miami, FL 33136-1096  
PH: (305) 585-7348

Fax: (305) 585-6397  
Primary Physician - Dr. Anne Burdick  
*email: Aburdick@med.miami.edu*  
Public Health Nurse - Ms. Gail Chepenik, R.N.  
*email: gchepenik@um-jmh.org*

### **NEW YORK HD CLINIC**

Bellevue Hospital Center  
Department of Dermatology  
Room 17-N-7  
462 First Avenue  
New York, NY 10016  
PH: (212) 562-6096  
Fax: (212) 263-6423  
Primary Physician - Dr. William Levis  
*email: William\_Levis@yahoo.com*  
Public Health Nurse - Ms. Aloys Cabrera, R.N.  
*email: cabreraa@bellevue.nychhc.org*  
Physical Therapist - Mr. Louis Iannuzzi, P.T., C.Ped.  
*email: lnuzzi@yahoo.com*

### **PHOENIX HD CLINIC**

Maricopa County Health Department  
1645 East Roosevelt Street  
Phoenix, Arizona 85006  
PH: (602) 372-6661  
Fax: (602) 506-6615  
Primary Physician - Dr. Ronald Pust  
*email: rpust@email.arizona.edu*  
Public Health Nurse -  
Physical Therapist - Tracy Carroll, MPH  
*email: tcarroll@email.arizona.edu*

### **SAN DIEGO HD CLINIC**

North Central Public Health Center  
2440 Grand Avenue  
San Diego, CA 92109  
PH: (858) 490-4400  
Fax: (858) 490-4405  
Primary Physician - Dr. T. O'Grady  
*email: togrady@ucsd.edu*  
Public Health Nurse - Ms. Carmen Rodriguez, R.N.  
*email: carmen.rodriguez1@sdcounty.ca.gov*

### **SAN JUAN HD CLINIC**

University of Puerto Rico  
Medical Sciences Campus  
School of Medicine - Dept. of Dermatology  
P. O. Box 365067  
San Juan, PR 00936-5067  
PH: (787) 765-7950  
Fax: (787) 767-0467  
Primary Physician - Dr. Pablo Almodovar  
*email: rcmdermatol@rcm.upr.edu*  
Public Health Nurse - Ms. Sonia Santos-Exposito,  
R.N.  
*email: smsantos@rcm.upr.edu*

### **SEATTLE HD CLINIC**

Harborview Medical Center  
2 West Clinic - 359930  
325 Ninth Avenue  
Seattle, WA 98104  
PH: (206) 744-2128  
Fax: (206) 744-5109

Primary Physician - Dr. James Harnisch  
*email: jpharnisch@comcast.net*  
Public Health Nurse - Ms. Virginia Ouellet, R.N.  
*email: ouellv@u.washington.edu*  
Physical Therapist - Tom McClure, PT, CHT  
*email: tmcmtpt@u.washington.edu*

### **TEXAS HD CLINICS**

Department of State Health Services  
Hansen's Disease Program  
P. O. Box 149347  
Austin, TX 78714-9347  
PH: (800) 252-8239 Option 5  
Fax: (512) 458-7451  
Officer Administrator: Kirbi Woods  
*email: kirbi.woods@dshs.state.tx.us*  
Ms. Linda Brown, Program Director  
*email: lindaj.brown@dshs.state.tx.us*

Dallas County Department of Health & Human Sciences  
2377 N. Stemmons Freeway, Suite 522  
Dallas, TX 75207-2710  
PH: (214) 819-2010  
Fax: (214) 819-6095  
Physicians - Dr. Jack Cohen/Dr. Sharon Nations  
*email: jack.cohen@utsouthwestern.edu*  
*email: Sharon.nations@utsouthwestern.edu*  
Public Health Nurse - Ms. Nancy Bernstein, BSN, RN  
*email: Nbernstein@dallascounty.org*

Houston Hansen's Disease Clinic  
Northside Health Center  
8504 Schuller Street  
Houston, TX 77093  
PH: (713) 794-9078  
Fax: (713) 384-7741  
Physician - Dr. Terry Williams  
*email: Tewill2391@aol.com*  
Public Health Nurse - Joan Taylor, R.N.  
*email: Joan.Taylor@cityofhouston.net*

Texas Center for Infectious Disease  
2303 S. E. Military Drive  
San Antonio, TX 78223  
PH: (210) 534-8857 ext. 2327  
Fax: (210) 531-4508  
Physician - Dr. Robert N. Longfield/Dr. Adriana Vasquez  
*email: robert.longfield@dshs.state.tx.us*  
*email: adriana.vasquez@dshs.state.tx.us*

Public Health Nurse - Ms. Debbie Mata, R.N.  
*email: debbie.mata@dshs.state.tx.us*

South Texas Health Care Center  
OPCL  
601 W. Sesame Drive  
Harlingen, TX 78550  
PH: (956) 423-0130  
Fax: (956) 444-3295  
Physician - Dr. Richard Wing  
*email: richard.wing@dshs.state.tx.us*

Public Health Nurse - Vacant

VOITURE NATIONALE  
777 North Meridian St., Suite 204  
Indianapolis, IN 46204-1065

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# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

## GET TO KNOW THE FORTY & EIGHT

The **Forty & Eight**, an honor society of veterans 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.



## FACTS ABOUT HANSEN'S DISEASE

### 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 Amauer 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 23 cases at the Gillis W Long Center at Carville, LA. Most patients in the US are treated under US Public Health Service grants at clinics in major cities or by private physicians.

(See 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.

"The editor is working on updating the information on this page, and it should be corrected by the next issue. We are sorry for any inconvenience."