

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

JAN - JUNE
2013
VOLUME 64 - 15



FORTY AND EIGHT PIN DESIGN CREATED TO SHOW THEIR 2013 PARTNERSHIP WITH THE STAR

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

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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Eyes Wide Open

By Mayra Olguin, Student, University of Houston, Graduate College of Social Work

For my first year field placement with the Graduate College of Social Work, I was placed at the Mental Health Mental Retardation Authority of Harris County (MHMRA). As a social work intern, I expected to gain clinical experience and a broader understanding of the agency as a whole, but I quickly realized that I needed to have an ongoing awareness of stigma. My field instructor, José Ramirez Jr., did not hesitate to show me how individuals affected by Hansen's disease are impacted by stigma, similar to how the mental health population and those with intellectual and developmental disabilities are impacted by it. Those individuals coping with mental illness do not want to be called "crazy" just like those with Hansen's disease do not want to be called the "L-word". Many of these individuals will often attempt to seek treatment for mental health symptoms through their primary care physician, or will refrain from seeking treatment at all, because of the stigma associated with seeing a "shrink". People do not question someone seeking treatment for diabetes or pneumonia, and I believe mental health treatment should be looked at just the same. It is simply a different kind of illness. In the past, individuals with Hansen's disease were often shunned and institutionalized, where they lived away from family and friends. The stigma associated with this institutionalization, parallels that experienced by people with mental illness who go to state hospitals, and/or people with Intellectual and Developmental Disabilities who go to state supported living centers.

During my time as an intern at MHMRA, I was provided with a variety of experiences throughout the different departments in the agency. One of these experiences included visiting a Home and Community Based (HCS) Services residence. HCS is a Medicaid waiver program which provides lifelong services to individuals with Intellectual and Developmental Disabilities, one of which includes community based living for clients in homes located in regular Houston neighborhoods. I was able to meet clients who were flourishing living in these homes, residing in their communities and even maintaining employment. The clients seemed to be content individuals who were successfully living amongst their community members. On the same day, I also visited Richmond State Supported Living Center, where individuals with Intellectual Disabilities were institutionalized in a place where many of them could possibly reside for the rest of their lives. It was difficult to see the striking difference between community inclusion and community exclusions, because I personally believe that clients do thrive in the least restrictive environment. Nonetheless, this is an experience that I will forever carry with me and one that will remind me to always strive for what is in the best interest of my client and advocate for their needs to ensure they have the opportunity to achieve a great quality of life.

At my internship, I have witnessed stigma and institutionalization affecting populations beyond those with Hansen's disease. My internship experience culminated in April 2013, when I, along with José Ramirez Jr. and other MHMRA professionals, presented at a workshop on MHMRA. As I presented to my peers and staff members, I discussed learning experiences from my internship, which included the stigma and institutionalization of the clients we serve. Sharing this knowledge with others helped to promote the awareness of stigma and the empowerment of others. Being proactive in reducing stigma will allow others to seek treatment without judgment, to be treated with respect and to live with dignity, and I hope to be able to continue to share this knowledge with others.

JOURNEY TO FIGHT STIGMA

By José Ramirez Jr.

In 2006, Mike Wood of the 40&8 surprised me with an invitation to serve as the Managing Editor of The Star. This invitation immediately opened up my memory cells to my seven year stay at the national leprosarium at Carville, LA as patient #2855. There is no denial that the diagnosis affected my physical and behavioral health and my parents were seriously impacted by the biblical implications of Hansen's disease. Conversely I was also positively influenced by the daily contributions made by the culturally and linguistically diverse staff of The Star.

I vividly recalled the hard work of other patients in completing the task needed to monthly mail the publication all over the world: design of cover, review of articles, selecting letters to the editor, informing the world about the most current treatments, and accompanying stigma. I also recalled the other residents in this family of 400+ patients who felt alone and voiceless after being separated by their families, in large part, because of myths surrounding this greatly misunderstood disease.

Upon recalling my experience at Carville, I accepted and made a promise to Mike that I would do all I could to resurrect the silent voices of my brothers and sisters who had lived at "Carville", some for many decades, until their death.

The following is a summary of my attempts during the first six months of 2013 to "radiate the light of truth about HD." Some of these efforts were done in concert with others.

On January 11, 2013, I was the speaker at the 33rd Annual C. J. Collins Symposium in San Antonio, Texas. The Worden Graduate School of Social Service is on the campus of Our Lady of the Lake University. Sisters from the Order of Divine Providence live at this beautiful university located in a neighborhood surrounded by brightly colored homes of Hispanic families. They dedicated their lives to teaching at Catholic schools throughout Texas, Louisiana, and Oklahoma. My co-hosts, Dr. William Rainford, Professor Cynthia Medina, and Sister Laverne Mettlach played a big role in allowing me to educate many about HD. Sister Laverne invited me to pray at their chapel, visit the special chapel of adoration, eat with her "sisters" in their simple dining hall, and sleep in the "VIP room"- a simple bed with a small writing table. I shared my personal journey with the sisters and they shared their warmth, humor, and desire to learn about "this biblical illness". Even as many were reaching their eighth decade on this earth they still wanted to know about HD in order to "teach" others. Their sensitivity reminded me of the beautiful sisters of the Order of Daughters of Charity, who used their nursing skills to care for us at Carville.

Dr. Rainford on the other hand, wanted me to educate fellow social workers from San Antonio and the surrounding military bases about the stigma that accompanies HD. My presentation was titled " Leprosy & Human Rights: A Model for Social Workers." This trip became even more special when I realized that the brother of Mary Ruth Broussard (Daigle) and his daughter were in the audience. Mary Ruth was my surrogate mother at Carville and became the "adoptive" mother of Magdalena, my wife. While I have learned to suppress my emotions when speaking about my journey, I was unable to contain my tears on January 11th.

On February 9, 2013, I celebrated my 65th birthday by sending out an email that on February 24th I would commemorate my 45th anniversary of admission to Carville. The readers of my email found words such as family, love, stigma, respect, educate, The Star.

On March 15, 2013, I was in Tokyo, Japan as one of 11 members of the International Working Group (IWG) on Leprosy and Human Rights. This unique group was hosted by the Nippon Foundation and the UN Goodwill Ambassador

for the Elimination of Leprosy. The goal of the IWG is to promote and protect the rights of persons affected by HD.

Ironically while in Japan the Cardinal from Argentina was selected Pope and chose the name of Francis. Stories quickly were posted on the internet about his sensitive acceptance of persons affected by HD. The IWG drafted a letter to Pope Francis to be delivered by a representative from the United Nations. The letter urged him to continue to speak out for those who are vulnerable to discrimination and who might be stigmatized because of disease (see letter in this issue).

In April, I was contacted by the History Channel to consider participating in an educational story about HD. The purpose is to educate the public about the difficulty in diagnosing someone with HD, and how stigma can impact their lives after diagnosis. This story is not yet complete.

May was a busy month... On May 7th I made a presentation titled “The Journey to Retaining Human Rights” at the UN International Coordinating Committee (ICC) on Human Rights in Geneva, Switzerland. Two other persons affected by HD from India, Vagavathali Narsappa and Guntreddy Vanugopal, co-presented with me and Yohei Sasaki, UN Goodwill Ambassador for the Elimination of Leprosy. Our goal was for the ICC to support our global appeal to end discrimination against persons affected by HD. The 200 member country representatives on the ICC unanimously endorsed the appeal. This appeal will be formally introduced to the United Nations body in New York City in 2015.

Upon my return from Geneva, my wife and I joined Marion Matsu, Administrative RN at the HD Clinic in Houston, at a meeting hosted by the Lazarus Society of Greater Houston. The Lazarus Society presented Ms. Matsu with \$5,000.00 worth of gift cards for persons assigned to the clinic for treatment who have limited financial resources for travel, food, and lodging. My wife and I made a brief presentation on the impact of stigma on persons affected by HD.

Then, Harpers Magazine published a story by Rebecca Solnit titled “The Separating Sickness; How Leprosy Teaches Empathy”. This was a lengthy story on the road taken by those affected by HD and those who participate in the treatment and research of HD. It is an article worthy of sharing with professional organizations for required reading on the topic of empathy.

In June, Pope Francis appeared to have reversed himself on reaching out to persons affected by HD by disallowing this affection with comments made to the Vatican diplomatic corp. Pope Francis is reported to have said that “careerism is leprosy,” i.e., the diplomatic corp. should focus on spiritual strength and not on their careers; otherwise they will be cursed with a label of outcast. Comments were sent to me from throughout the world and all were outraged with his analogy, especially since he has been quoted to say, “I need to live among the people.” To date there is no response to my objections and that of others.

At the beginning of June, two unique stories about HD were published in scientific journals. One related to genome sequencing which revealed that the HD bacillus has not changed in many centuries. Conversely, scientists have also discovered that the human DNA underwent some changes during the middle ages. Scientists discovered that humans were able to ward off the growth of the bacilli and thus dramatically decrease the number of leprosy cases throughout Europe.

For those of you affected by leprosy, our life line continues to surprise us. The Nobel Prize for medicine will likely be awarded to the person(s) who prove how this tiny bacillus is transmitted.

The fight against stigma is a daily challenge and efforts will continue to eventually win this battle.

40 & 8 SUPPORT OF CARVILLE AND *THE STAR*

Joseph Steil, Nationale Directeur Carville Star and Elizabeth Schexnyder, NHDM Curator

The 40&8 has a long history of supporting *The Star*. The impetus for this occurred in 1931 with a group of 23 U.S. veterans with Hansen's disease at Carville, including Stanley Stein. These veterans were asking for a decent infirmary building, a recreation hall, facilities to play sports on the hospital grounds, and more contact with the outside world. The Louisiana State Commander of the American Legion, Sam Jones, along with other Legionnaires, visited the Carville veterans and listened to their complaints and needs. The veterans were told to form an American Legion Post because there is strength in numbers. With a million Legionnaires behind them, their influence would be greatly increased. Sam Jones, who later became the Governor of the State of Louisiana, attended the first meeting of the Carville American Legion Post.



40 & 8's Presenting Printing Press in 1947

From *The Star's* outset the 40 & 8 provided the linotype machine, a printing press, bundling press, and all the modern equipment needed to produce a professional looking publication. Stanley Stein, *The Star's* founder and first editor, said of the 40 & 8, "It was their adventure in humanity, and there is no way that we can ever thank the 40 & 8 for all they have done." The 40 & 8 took over the Carville Star program in 1944 and has maintained it to the present, making it the second oldest program in La Societe. 1994 marked the 100 year founding of the Gillis W. Long Hansen's Disease Center in Carville and the 50th anniversary of the 40 & 8's sponsorship of the patient-published Star Magazine.

Along with supporting *The Star*, the 40 & 8 brought fun and entertainment to Carville's

patient residents with cook-outs, fishing rodeos, and camaraderie throughout the years.

The Carville Museum opened in 1996. The 40 & 8 took a more active role when Chef de Chemin de Fer 2002 Bob Kaseman visited the museum during his term of office. Through his efforts and the 40 & 8 Voyageurs and Dames of the La Femmes (La Society de Femmes is a fraternal organization of women founded in 1963 for the sole purpose of supporting the programs and principles of the 40 & 8) donations totaling \$10,000 were made in 2002 and 2003 to help support the museum's mission of preservation of documents and artifacts. It is now a 5-star museum with artifacts and archives, and Stanley Stein's office files from *The Star*. The 40 & 8's donations of preservation supplies and fire-safe cabinets will keep these available for generations to learn about the history of *The Star* and the research and treatment of Hansen's disease.

In 2005 Chef de Chemin de Fer Mac McCarthy spearheaded a project to install a new banner and a permanent sign on the front of the museum. The 40 & 8 has also provided the museum with its own flag with the 40 & 8 logo on it



40 & 8rs With V-340 Loci Celebrating With Patients



40 & 8's Presenting Museum Flag To Elizabeth Schexnyder

symbolizing our support. Through internal fundraising, the 40 & 8 Voyageurs and Dames of La Femmes made donations to the museum that helped restore two valuable paintings from 1947: Mothers' Day and Bundling the STAR.

La Presidente Nationale for 2011-2012 was Sandy Wood, and she named the Carville Museum as her Presidente's Project. The subsequent donation Sandy presented to the museum is being used for the purchase of preservation supplies to protect *The Star* archives, preservation papers and plastic products for storing documents, photographs and artifacts. These are all costly items and due to anticipated NHDP budget cuts this year, the museum can certainly put this donation to good use.

Mr. Pete, who arrived as a patient in 1951, has been a resident at Carville for over 60 years. He chose to stay at Carville in 1999 when the NHDP relocated to Baton Rouge. He is the 7th *Star* Editor and is the NHDP Museum Ambassador. If you visit the NHDP Museum, Mr. Pete will be there to assist in your tour, tell jokes, and relate his experiences as a resident.



La Presidente Nationale Sandy Wood Presenting Donation To Elizabeth Schexnyder and Mr. Pete

In 2007, a 40 & 8 donation was used to create a stone monument that was placed in the current Carville Patient's Cemetery. In 1922, a monument was erected with the names of over 130 patients who were buried at the quarantine hospital between 1895 and 1922. This monument stands in the "front quad" of the compound away from the current cemetery and inaccessible to most. Research in the museum archives verified that patients listed on the monument were still buried on this spot—which is the site of the first patient cemetery; the individual crosses had been removed when the stone monument was installed, but the burials remain undisturbed. Now, the duplicate stone stands where all visitors have access. At the February 2009 dedication of the stone, over one hundred people present—Voyageurs, Dames, 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. With the addition of this newly dedicated monument, visitors will be able to view the names of patients buried at Carville from 1895 to 1922.



Elizabeth Schexnyder and Duplicate Monument in Patients' Cemetery

Currently, the 40 & 8 has pledged support for the purchase of interpretive signs in the Carville Historic District. The museum is also expanding its outreach by developing a *Carville Historic District Welcome Center* in a tiny free standing building (12'x12') built when the State of Louisiana ran the site as the *Louisiana Leper Home*. The tiny building was used by the Daughters of Charity for many different activities including greenhouse, catechism classroom, and arts and crafts; it was sometimes called "The Tea House". Now it will hold exhibits on Carville history that will be accessible to after-hours visitors.

There are many ways the 40 & 8 and La Femmes support the Carville Star Program including:

Star Subscriptions - Subscriptions are available for \$2.00 per year. *The Star* is published twice a year, and provides information on the treatment and medical research advancement of Hansen's disease and articles on the history and support of the 40 & 8.

Buy A Country - A donor subscription plan that allows a Voiture or Cabane (or an individual Voyageur or Dame) to donate \$50.00 and send 12 one-year subscriptions to a specific country of the donor's choice.

Buy A Clinic - A donor subscription plan that allows a Voiture or Cabane (or an individual Voyageur or Dame) to donate \$50.00 and send 25 one-year subscriptions to a specific clinic of the donor's choice.

The Star Maintenance Fund - Supported by the sales of Carville Star Pins.

General Donations – Supporting the overall Carville Star Program

The Voyageurs of the 40 & 8, along with the outstanding support from the Dames of La Societe de Femme, are proud to have supported *The Star* from 1943 to the present. From the original presses and type setters, to the new modern full color format available on the Web, the 40 & 8 is ensuring that research on Hansen's disease continues to be distributed around the world.

The Legislative History of Leprosy: A New Collection for Carville's Museum

By Elizabeth Schexnyder, Curator, National Hansen's Disease Museum

I have come to understand that the stately buildings and security fences of "Carville, the National Leprosarium" were built using the bricks and mortar of local, state and federal legislation as well as standard construction materials. To truly understand why Carville's history unfolded as it has, it is necessary to examine the legislative history of leprosy (Hansen's disease) in the United States.

Our museum's exhibits and collections evoke important and poignant questions from visitors and researchers every day:

- *Why was there a high fence with barbed wire around the hospital grounds?*
- *Why couldn't patients at Carville vote?*
- *Why are some patients buried in the hospital cemetery and others buried back home?*
- *When did the rules change to allow patients at Carville to marry one another?*
- *Why couldn't a patient keep her new born baby with her at the hospital?*
- *Why did "Carville" close?*

To provide a clear answer, I had to locate and assemble the laws that built Carville. I found most of the answers scattered within our own collections: in the **Public Health Reports** and **International Journal of Leprosy**, for example. **The STAR**, Carville's patient-published magazine, has championed liberalizing legislation affecting those with leprosy from its rebirth in 1941. Some STAR articles included in the new collection are Hospital Rules and Regulations, a 9-part series by Dr. Guy Faget (August 1942 to April 1943) and the development and passage of the National Leprosy Act (1949, Vol. 8, No. 6). Digital versions of The STAR are available through Louis Digital Library: www.louisianadigitallibrary.org. Search under collection name: [The STAR: Radiating the light of truth on Hansen's disease](#).

The gathered legal documents needed to be crafted together with care to make the collection user friendly and comprehensive. I received research assistance from Laureen Lentz, a 3rd year law student at Loyola in New Orleans, in locating and assembling the legislation. Additional materials— correspondence and published articles—collected from Tulane, Louisiana State University and the Daughters of Charity's Archives became the hammer and nails of the *laws/construction/collection* metaphor.

Our legislation collection contains laws from 1866 to the present. It is organized chronologically and by legislative origin: local, state, territory, and federal. A finding aid and digital versions of most of the documents are available for researchers.

Excerpts from the collection:

- **1892, Act 85.** LA State Legislature, Louisiana's "lepers" to be quarantined to selected location.
- **1894, Act 80.** LA State Legislature. Dr. Isadore Dyer, President of LA Leper Home Board of Control, presented an administrative plan for the Louisiana Leper Home.
- **1896, Contract.** LA Leper Home Board of Control & Daughters of Charity for administration and nursing duties at the Louisiana Leper Home.
- **1917, US Senate Bill 4086.** Established a National Leprosarium in Carville.
- **1944, Public Health Services Act.** The US Surgeon General is authorized, upon the request of any health authority, to send for any person within the jurisdiction of such authority who is afflicted with leprosy and to convey such person to the appropriate hospital for detention and treatment."
- **1945, American Public Health Association** advised against isolating people with leprosy.
- **1946, State of Louisiana** gives patients the right to vote.
- **1947, US Public Health Service** removed HD from the list of quarantine-able diseases which required a travel permit.
- **1948, the US Public Health Service** removes the barbed wire fence from the facility, and the first active patient was released to the care of her private physician. Also, the USPHS officially recognized the name Hansen's disease as a replacement for the term leprosy.
- **1957, State of Louisiana** removes HD from list of quarantine-able diseases.
- **1997 PL 105-78 (Baker Bill),** Relocation of Gillis W. Long Hansen's Disease Center. In 1999, the federal government transferred the leprosarium to the State of Louisiana.

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PHYSICAL LOCATION: National Hansen's Disease Museum, Gillis W. Long Center, 5445 Point Clair Road, BLDG 12, Carville, LA

Leprosy and Pope Francis

The following letter is referenced in the article “Journey to Fight Stigma”. The letter was composed and mailed by members of the International Working Group on Leprosy and Human Rights while attending a meeting in Tokyo, Japan. Members of the IWG signed this letter on April 19, 2013 and include: José Ramirez Jr.(U.S.A.), Barbara A. Frey (U.S.A.), Yozo Yakota (Japan), Dr. Vesselin Popovski (Japan), Javed Abidi (India), P.K. Gopal (India), Artur Custódio Moreira de Sousa (Brazil), Támara Biolo Soares (Brazil), Cecilia R. V. Quisumbing (Philippines), Menberu Adane Yihunie (Ethiopia), Deepika Udagama (Sri Lanka)

Your Holiness,

We, the undersigned, as members of the International Working Group on Leprosy and Human Rights, which brings together noted experts and advocates from around the world to promote and protect the rights of persons affected by leprosy, congratulate you on your recent election as the successor to the Chair of St. Peter to lead the Holy Roman Catholic Church.

We join in the great spirit of optimism that accompanies your ascension to Holy Office, based on your well-documented compassion for the poor, for persons affected by HIV/AIDS, and for other marginalized sectors of society. Your Holiness, we particularly appreciate your emphasis of the special relationship that Jesus Christ had with stigmatized persons in the Gospel, including persons who were affected by leprosy. In this way, you have spiritually embraced all persons affected by leprosy. We deem this particularly fitting of the name you have chosen for your Papal leadership, since St. Francis of Assisi is said to have physically embraced a person affected by leprosy at a key point in his spiritual life.

Throughout the centuries, the Catholic Church has done much mission work related to leprosy, and we celebrate the efforts to the Catholic saints including Father Damien and Sister Marianne Cope at the leprosy settlement in Hawaii, and the work of Fr. Luis Ruiz, SJ, in Macau. More recently, each year, on World Leprosy Day, the Vatican has issued statements to support the elimination of the stigma and discrimination accompanying leprosy and your predecessors have also had a practice of meeting every year with persons affected by the disease.

In our world today, even though medical solutions are already in place to cure leprosy, persons affected by leprosy continue to be impacted by social stigmatization and many forms of prejudice. Because of this, in 2009, religious leaders from around the world joined together to support the Global Appeal to End Stigma and Discrimination against People Affected by Leprosy. These included His Eminence Cardinal Javier Lozano Barragan, then-President of the Pontifical Council for Health and pastoral Care of the Vatican; His Eminence Guadencio Borbon Cardinal Rosales, then-Cardinal Archbishop of Manila; the Most Reverend Desmond Tutu, Archbishop Emeritus of Capetown; and His Holiness, the Dalai Lama, among others.

Growing international recognition of these issues led to a resolution adopted by the United Nations General Assembly on 12 August 2010 endorsing the Principles and Guidelines on the Elimination of Discrimination of Persons Affected by Leprosy and their family members. These Principles and Guidelines confirm the important role that religious leaders play in promoting the dignity of all persons affected by leprosy, specifically noting, “how addressing leprosy in their teachings or written materials may continue the elimination of discrimination against persons affected by the disease and their family members.”

Your Holiness, the International Working Group on Leprosy and Human Rights is cognizant of the myriad of heavy responsibilities and duties you carry in your new office. Still we strongly hope you continue to speak out for those who are vulnerable to discrimination and who may be stigmatized because of disease, disability and any other basis. In particular, we hope that you will join us to call for worldwide respect for and protection of the human rights of persons affected by leprosy and their families, and we stand ready to support you in that call.

Please accept our best wishes as you assume your Holy Office.

Respectfully,

José Ramirez Jr.(U.S.A.), Barbara A. Frey (U.S.A.), Yozo Yakota (Japan), Dr. Vesselin Popovski (Japan), Javed Abidi (India), P.K. Gopal (India), Artur Custódio Moreira de Sousa (Brazil), Támara Biolo Soares (Brazil), Cecilia R. V. Quisumbing (Philippines), Menberu Adane Yihunie (Ethiopia), Deepika Udagama (Sri Lanka)

Some Childhood Memories from Carville in the 1960s

By J.C. Callaway, Ph.D.

I was not born in Carville, but my earliest memories are from Carville. My father had moved us there in the spring of 1959 to take up a medical position with the USPHS, which included an extra \$125 per month as hazard pay. We lived in a brick house on the edge of a golf course, inside the fenced hospital station. This was an idyllic situation for Dad; an avid young golfer who was just beginning a medical career in orthopedic surgery, and for Mom, who birthed three more children in the years we were there. Sometimes I wondered why my siblings were born in Baton Rouge, rather than the Carville Hospital, which was just a few hundred yards away. Medical professionals at that time already knew that the risk of infection was very low, yet the Carville facilities were not available to those of us who were not already patients.

Not yet in school, my life seemed to be an endless summer for the next five years. During the autumn time we picked up pecans from the golf course, and sometimes brought them to Carville's General Store. Chester Carville once jokingly asked my Mom if we were allowed to sell the pecans we had collected, and she suggested that he ask my brother and me about it. Matt and I just stood there, not knowing what to say, and then the adults laughed, as they often do when young children do not understand the gravity of a moment. Mr. Carville gave Matt and me a stack of quarters each for our pecans. We were thrilled to have our own cash money, and quickly spent most of it on the spot.

As children, we did not know about the purpose of the Carville Hospital, much less the peculiar restrictions on almost anything leaving the Station, especially food items. Another early memory has me coughing into a fresh Petri dish that Dad brought home from the hospital one day. We all coughed into our own dish. He wanted to teach us about germs. After a few days, we could see bacteria growing on the surface of the agar. One neighbor kept a few white mice in his house. It seemed like a normal thing to do. Another neighbor once filmed an alligator in the lake nearby. I also remember a day when many neighbors turned out to hand plant a new putting green next to the Johnwick house, one grass shoot at a time. It was a mud fest for the kids. (*Dr. Edgar Johnwick was the Medical Officer in Charge*)

The Carville of the early 1960s, to my recollection, was a small, tight-knit community with plenty of children of various ages. Some of our movements were restricted, but this is typical for all children. The limits were clear enough, and there was no reason for us to wander or ride our bicycles too near the hospital. From a distance, we could sometimes see the Sisters gliding from one building to another. Another place that was out of bounds to people my age was a small lake, which had been visited by at least one alligator. A book mobile visited the Station on certain days, and we made the occasional trip to Carville's General Store- a place of awe and wonder for any young child of that time.

As children, we could not easily leave the fenced station on our own, and we were certainly not allowed to cross the road to play on the levee. This became especially clear to me soon after returning home from a solitary walk to the river, for the better part of an entire afternoon. I may have been four years old at the time. My brief enjoyment was quickly replaced by a sudden realization that crossing the road without an adult, and especially visiting the river alone, was a very serious matter to many parents and other adults on that day.

The Mississippi River was just on the other side of the levee, and the levee was just over a stone's throw away

from our house. Sometimes our family would walk to the levee and visit the bank of this great river. A visiting doctor from Samoa was known to swim across to the other side and back, just for fun. On some occasions, Dad let us shoot his 22-caliber rifle during our walks to the river. The sights were off, and he always had to remind us to aim down and to the right, as if it really mattered.

As a family, we sometimes visited parts of the hospital, perhaps for Sunday school or other social occasions. Otherwise, my strongest memories were of the pools; a wading pool for children and the larger pool, both fenced and both adjacent to a shaded sandy playground, and all within easy walking distance from our house. The hot summer walks to and from the pool, the spiny black caterpillars that sometimes overran the cement sidewalks and the cicadas singing their electric grinding buzz; these impressions remain on my soul. This is where I learned how to swim, and my mother has literally taught thousands of others how to swim since that time.

In 1964, my father applied for an orthopedic residency at Tulane, and by that summer our family had moved from Carville to a suburb of New Orleans. Life began to change quickly after that, and I entered the first grade that autumn. As my worldview began to expand at rapid rate, I often drifted back to the blissful memories of my earlier childhood in Carville. Last November I had the opportunity to visit and see how little has changed in the “old” neighborhood, even with the addition of so many new buildings in the area. I also had the privilege to meet Mr. Peterson, a former patient and true survivor who lived an entirely different life in this special place called Carville. There was not the opportunity for us to have meet 50 years ago. Fortunately, the methodical reasoning and perseverance of medical science has helped to sweep away another fog of ignorance from the landscape of humanity.

18 June 2013

J.C. Callaway, Ph.D.
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Simeon Peterson & Jace Callaway, National Hansen's Disease Museum in Carville,
November 2012

THE SHOW MUST GO ON: The Many Faces of the Ex Officio STAR Editors

By: The STAR Editorial Board

This article is the final in a series on Editors of The STAR.

After the death in 2004 of Emanuel Faria, the last on-site editor of The STAR, representatives from the Forty and Eight and The STAR Editorial Board decided that Stanley Stein's work should not stop. So, in order to ensure "patient oversight" of the publication, a temporary editor was appointed. This gentleman, Wilman Williams, was admitted to Carville as a teenager and worked at The STAR in different capacities. Wilman realized the 1999 Executive Order signed by President Clinton allowing patients to leave the facility and receive a stipend meant that the "old guard" would no longer be available to provide needed support for The STAR. So, Wilman enlisted the assistance of others who continued their contact with The STAR and remained residents at Carville. Wilman did a magnificent job of getting stories for publication and "Radiating the Light of Truth on Hansen's Disease".

In 2006, Abel Aparicio took over the responsibilities of serving as Ex Officio Editor until his death in 2010. Abel, having a unique perspective of Carville and its residents, guided The STAR by providing suggestions for stories. His bilingual skills, talent with the golf clubs, and gentle demeanor allowed him to capture the essence of life at Carville and relayed that message to others who transferred his words into print.

During Abel's tenure as Ex Officio Editor, José Ramirez, Jr. was invited to serve as Managing Editor of The STAR. Ramirez sought the advice on stories from the Editorial Board comprised of Dr. James Krahenbuhl, Irma Guerra, Ymelda Beauchamp, Elizabeth Schexnyder and a representative from the Forty and Eight, currently Joe Steil.

José Ramirez was admitted to Carville at age 20, and was active with many patient organizations during his stay. José was a trailblazer as well, completing his college education while still "under treatment." Today, his work as a licensed social worker, advocate, USA Coordinator for IDEA, and consultant to numerous anti-leprosy organizations allows him the opportunity to secure articles for The STAR ranging from technical research to human interest. He has served as Managing Editor since 2007 and lives in Houston, Texas.

In 2010, the Editorial Board appointed Simeon Peterson to serve as the Ex Officio Editor of The STAR. Mr. Peterson is also known as "Mr. Pete," "Dr. Pete," and "Mr. Ambassador." The title that best fits him is "Mr. Ambassador" as he is able to demystify the negative images of Hansen's disease simply by talking about the many challenges he has overcome through his faith, his trust in others, and respect for all. Mr. Pete always participates in the telephone conferences of the Editorial Board, makes suggestions for articles, and has been a regular contributing co-author on STAR stories. Mr. Pete's experience as a patient has been featured in several books and many journal articles about Carville. "Young at heart" and wonderfully engaging as a tour guide, Mr. Pete has a special knack for bonding with young Carville visitors. The running joke at the museum is that "if kids could vote, Mr. Pete would be President!"

No one has a "crystal ball" that can predict the future of STAR Editors, but one thing is certain—the on-going support of the Forty and Eight to keep alive Stanley Stein's and the STAR's mission of "Radiating the Light of Truth on Hansen's Disease".

Carville Tour

By Barry K. Bovee, Chef de Chemin de Fer 2012-2013

Each year the Chef de Chemin de Fer, the National Commander of the 40/8, has the opportunity to visit the Carville Museum. As Chef this year I made the visit along with Nationale Director Joe Steil and other 40/8ers.

We were met by museum director Elizabeth Schexnyder and given a tour of the grounds and museum. After the tour and luncheon we viewed a movie of the history of Carville, some



Dr. James Krahenbuhl, Elizabeth Schexnyder, and Barry Bovee at Carville Museum

of the patients that lived there, and the advancements that have taken place in the treatment of this terrible disease. You can read all you want about this facility, but unless you have actually been there you cannot

have any idea or feelings of what it must have been like to be a patient that had to live there. These people were considered outcasts in their communities and once sent to Carville it would be the only place they could be for the rest of their lives. Although this disease was not contagious, the outside community would not accept anything coming back out of the area that used went in. Things such as Coca-Cola bottles had to stay within the compound area. As a result of this the hospital became self-sufficient raising much of their own food and making a lot of other things so as to be independent of the outside world.

As you tour the grounds, museum and watch the movie it is very evident how much the 40/8 has helped with the research on Hansen's disease and also in the support of the facility in the past. Everything that we have helped with, such as the printing press for the Star, is marked in the museum showing our support.

Although great strides have taken place with Hansen's disease, it still exists. The Carville facility today is the home of

the museum and the site of the old grounds and hospital which has many visitors each year. The 40/8 with the sale of pins, Star subscriptions, sponsoring a country or clinic, each year is proud to be a part of the continued research and putting out information through the Star. Also with our support of the museum, the hardships of the patients and history of this dreaded disease will not be forgotten. I would like to thank all the doctors, nurses and others that had the courage to work in this area that was so unknown for many years.

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HANSEN'S DISEASE CLINICS

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Emory MidTown Hospital
550 Peachtree Street NE
7th Floor MOT
Atlanta, GA 30308

PH: (404) 686-5885 Fax: (404) 686-4508

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PH: (404) 686-5885

Public Health Nurse: Roberta Dismukes, RN
email: roberta.dismukes@emoryhealthcare.org
PH: (404)-320-6662 PH: (404) 686-7668

BOSTON HD CLINIC

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Burlington, MA 01805

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Primary Physician - Dr. Samuel Moschella
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CHICAGO HD CLINIC

University of Illinois
College of Medicine at Chicago
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808 S. Wood, RM 376 CME
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MARTINEZ HD CLINIC

Contra Costa Regional Medical Center
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2500 Alhambra Avenue
Martinez, CA 94553

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Community Health Worker - Maria Soto
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ACC East – 2nd Floor
Department of Dermatology
Miami, FL 33136-1096

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NEW YORK HD CLINIC

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Physical Therapist - Louis Iannuzzi, P.T., C.Ped.
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PHOENIX HD CLINIC

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Phoenix, Arizona 85006

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Public Health Nurse - Eileen Smith, RN
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Physical Therapist - Tracy Carroll, MPH
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5055 Ruffin Road, Mail Stop: N-513
San Diego, CA 92123

PH: (858) 573-7338 Fax: (858) 573-7325

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School of Medicine - Dept. of Dermatology
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Primary Physician - Dr. Pablo Almodo'var
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Public Health Nurse - Sonia Santos-Expo'sito, RN, BSN
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Primary Physician - Dr. James Harnisch
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Public Health Nurse – Marlene Skinnell, RN
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Physical Therapist - Tom McClure, PT, CHT
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Outreach Clinic of Washington County
614 E. Emma Avenue, Suite 247
Springdale, AR 72764

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Primary Physician: Linda McGhee, MD
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Public Health Nurse - Sandy Hainline Williams, RN
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Hawaii State Department of Health

Hansen's Disease Community Program

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Program Manager: Lori Ching, RN

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email: lori.ching@doh.hawaii.gov

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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, 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 difficulty and counteract most of the fears generated by the folklore surrounding this disease.

HD affects the skin, peripheral nerves, and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, and the 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 2008 the World Health Organization reported that there were 212,802 new cases of HD worldwide. In 1993, there were 591,000 new cases reported, and in 1992, 690,000 new cases. 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 who are still living. This includes approximately 3,300 cases currently receiving medical treatment for HD by the NHDP Ambulatory Care Program Clinics or private physicians with assistance from the NHDP. There were 150 new cases reported to the registry in 2008. California, Hawaii, Louisiana, Florida, Massachusetts, and New York contributed the largest number of cases in 2008.

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 95 % 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, Multidrug Therapy (MDT), which includes dapsons, rifampin, and clofazimine, is the recommended treatment for HD in the U.S. The rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Treatment rapidly renders the disease non-communicable by killing nearly all the bacilli within a few days, although it takes a number of years for the bacilli to be cleared from the body. This slow process is what can cause a condition known as "reaction," which can cause inflammation of the peripheral nerves, leading to nerve injury, pain, loss of sensation, and muscle atrophy. If not treated promptly, this process can cause deformity and disability.

NHDP SERVICES Website: www.hrsa.gov/hansens