

# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

JULY 2017 -  
DECEMBER 2018  
VOLUME 64 - 24



## **Simeon Augustus Peterson (1928-2017)**

**One GIANT in the World of Hansen's Disease**

**Remembering "Pete" Page 3  
Cover Photo by Vickie Joseph**

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease. 2.) Serve as advocate for those who have experienced or been impacted by HD. 3) Foster self-empowerment of those who have experienced HD.

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### 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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## One GIANT in the World of Hansen's Disease Simeon Augustus Peterson (1928—2017)

by Pam Fessler NPR

<https://www.npr.org/2017/12/28/573844426/confined-by-leprosy-but-open-to-the-world-remembering-ambassador-mr-pete>

**Simeon Augustus Peterson**, called "Mr. Pete," was not famous, but he was a much loved fixture in the small, isolated Louisiana community where he spent most of his life. And where he eventually became its emissary to the outside world.

Mr. Pete died in November 2017 at 89 after suffering from cancer.

He spent 83 of those years living in institutions. When he was only six years old in the Virgin Islands, he was diagnosed with Hansen's Disease, commonly known as leprosy. In those days — the 1930s — that meant a life sentence, stuck behind fences and gates, shut off from family and friends, stigmatized and shunned.

"If they know you have the disease, they treat you bad," he recently said of that time in his life. "They don't want to have anything to do with you."

It was scary for the little boy, confined to a leprosy hospital on St. Croix. He was frightened he'd become like some of the older patients who had lumps on their faces, although he never did. He was also lonely. His mother visited once a month, but wasn't allowed to touch him because of a misguided belief that the disease was highly contagious, which it is not. Ninety five percent of humans are naturally immune.

When the opportunity came in 1951 for Mr. Pete to transfer to the U.S. leprosarium in Carville, La., where he could get better medical care, he jumped at the chance. At age 23, he was eager for adventure, and needed surgery for his hands, which the disease had slowly crippled.

The Carville hospital, which housed about 400 patients when Mr. Pete arrived, was located along the Mississippi River, on a sprawling former plantation dotted with magnificent oaks and pecan trees. He would still be confined, but there was also a vibrant patient community there, with movies and mardi gras parades, dances and even a newspaper.



**Mr. Pete The ambassador riding his bicycle on the two mile "road" connecting all of the buildings at Carville/Photo by Vickie Joseph**



**Mr. Pete waiting for a call to conduct a tour for visitors/ Photo by Elizabeth Schexnyder**

For Mr. Pete, there was also a purpose. He worked at the hospital as an elevator operator for 60 cents an hour, transporting patients and doctors to appointments and therapy sessions. Later, he got another job pushing those confined to wheelchairs around the sprawling complex, and helping blind patients, of which there were many, maneuver their way along the miles of screened in walkways that connected Carville's buildings.

Mr. Pete was also often one of the first people new patients met when they arrived at Carville, frightened and confused. He

would try to put them at ease, assuring them they'd be okay.

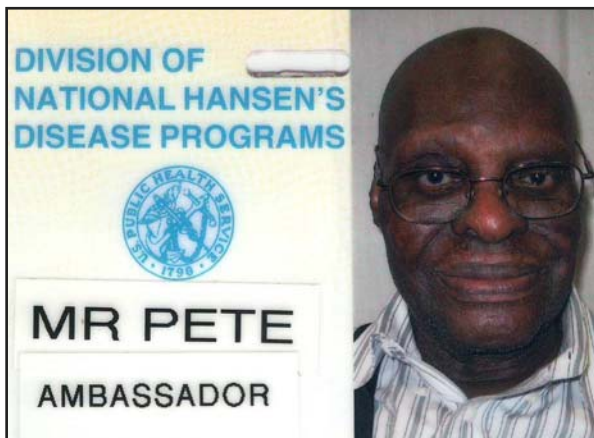
A cure for Hansen's Disease was discovered and perfected in the last half of the 20th century. But when the government decided to shut the hospital down in 1999, Mr. Pete was among those who refused to leave. Like other patients who had been confined for so long — often against their will — he had nowhere else to go. He paraded in protest, carrying a sign on his bike that read: "I don't want to leave. This is my home."

The government relented, and allowed those who wanted to stay to remain under its care. That's when Mr. Pete got his final job, as ambassador of Carville. He would greet visitors at the National Hansen's Disease Museum on the grounds, and talk to them about the long misunderstood disease and the lives of those who got it. He told the curious and concerned that there was no reason to be scared, pointing out that no doctor or nurse who worked at Carville in over 100 years had ever contracted leprosy, and that the disease was now easily cured.



Ambassador Peterson serving as guide at the HD Museum for students from Boston University/Photo by Elizabeth Schexnyder

Museum Curator Elizabeth Schexnyder called Mr. Pete a "gem." She said children especially were mesmerized. He was witty and charming, a real character who could be seen bicycling around the complex, wearing his signature suspenders and coordinated hat.



ID badge for "official" designation of Ambassador Peterson/Photo by Elizabeth Schexnyder

I met Mr. Pete last year at a nursing home in Baton Rouge, where he and a handful of remaining patients had come to live out their final days. He was still giving media interviews, talking to journalists from around the world about living with leprosy and the stigma that persisted long after the disease was gone.

What struck me most was that a man who had what many would consider to be a tragic life, thought his life was pretty good. He was almost indignant when I asked if he'd ever wanted to leave Carville, to be free, to go out on his own, once he was cured. "Nah. This is my home 'til I die," he said.

While he might have been a pariah in the outside world, inside Carville he could be himself. He didn't have to explain his deformed hands. No one recoiled in fear. Why be depressed, he asked? He chose to be happy.

Mr. Pete died in November 2017, outliving everyone else in his immediate family. And he got his wish, to be buried with members of his other family, under the pecan trees at Carville.

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*Fifty years ago I was admitted to what was then known as the United States Public Health Service Hospital. My stay lasted seven years but one of the persons who helped me through the dreariness of being institutionalized was Dr. Pete as I called him since our first introduction. I called him Dr. Pete because he was always feeding me "drugs" of hope, compassion, joy, honesty and assurances that any feelings of self-doubt "would eventually pass." He continues to live in my life.*

*José Ramirez, Jr.*

## Kofi Nyarko awarded Wellesely Bailey award

IDEA is pleased to announce that Kofi Nyarko, IDEA Ghana Representative and IDEA Board Member, has been awarded the 2018 Wellesley Bailey award for "Courage, Achievement and Outstanding Contribution to the Cause for Leprosy." This award is given to two individuals in memory of Wellesley Bailey, the founder of The Leprosy Mission International. In October, Kofi traveled to Ethiopia along with his son Kojo to receive the award.

Kofi was nominated by Nana Abura Asankomah, III, Chief, Central Region of Ghana, and IDEA, for helping over 800 people return to their homes and communities after being separated from their families--some for up to 40 years--because of leprosy. Additionally, through his country-wide talks on radio and television, and work in churches, schools and festivals, discrimination and stigma have been greatly reduced in Ghana.

In his nomination by IDEA, Anwei Law wrote, "Kofi's life is a testimony to the fact that one is not simply defined by the challenges one faces, but how one responds to such challenges. He has followed through with this commitment in his profession as a teacher to children with special needs, and now as an internationally recognized advocate for people affected by leprosy."



*Kofi is a "brother" to all and is a role model to his sisters and brothers who have experienced Hansen's disease. Our voices are heard through him as he participates on ILEP's "Persons Affected" Panel, IDEA Board and SMHF presentations. He is one of our many international celebrities always giving and never asking for anything in return. A Hero in the World of HD.*

*José Ramirez, Jr.*

# THE BUMPY ROAD TO KICKING STIGMA

By José Ramirez, Jr.

The road to kicking stigma has been treacherous, peopled by the fearful and the feared. As I assume the editorship of The STAR, I wish to reflect on that bumpy passage.

The fear of, or stigma against, persons who have experienced Hansen's disease, more commonly known as leprosy goes back to pre-biblical times. Many phenomenon, including leprosy, have been difficult to explain and have evolved into legends, curses or fearful events. During pre-biblical times eclipses (lunar and solar), floods or tsunamis, or bodily sores have given rise to fear. This latter fear has been witnessed globally and regrettably, fiercely linked to those closest to us on a daily basis such as family and friends. As a result of my own experiences I have been inspired to define stigma as "an act of labeling, rejection, or unexplained fear of a person."

The fear of persons with leprosy became more descriptive and punitive as humans banished others or inflicting emotional and physical pain on them. As story telling (voice) became more powerful through the art of letters, this stigma became codified. One such example comes from the Book of Leviticus or as I like to reference it, the Book of Rules. In Leviticus, there is a list of things that a person suspected of experiencing leprosy was not allowed to do, such as travel on a public road, drink from a common fountain, enter a public building, etc. This list is a complete contradiction to the Ten Commandments (love thy neighbor) and presents an oxymoron to the human mind. The reason for creating the list of "do nots" is because persons with leprosy are erroneously perceived to be punished for some unknown sins committed.

This false equation with "Sins committed" has caused severe emotional pain and trauma to those impacted by the illness, including family members of those with leprosy. My own mother experienced such trauma upon my diagnosis and up until the moment before she died, believed that God was punishing her through me for some unknown sins she had allegedly committed. She died with a "clean soul" after hearing from me that Pope John Paul had referred to all of us throughout the world with leprosy as his "brothers and sisters."

This statement by Pope John Paul reminds me of the saying about what God won't ask after we die: God won't ask in what neighborhood you lived, but he will ask how you treated your neighbors. The HD bacillus crosses oceans, mountains, deserts, tall buildings, and everything else throughout the globe so symbolically we are all neighbors.

My mother was not the only mother traumatized by a child's diagnosis nor will she be the last. Stories passed on from generation to generation of segregated graves, letters, songs, art, institutionalization, isolation, erroneous images, paralyzing labels, and a multitude of other forms of documentation have perpetuated the fear of persons with leprosy and kept the swords of stigma alive.

There is so much history documenting the inhumane treatment of persons affected by leprosy that it would take a series of documentaries to accurately describe the eternal pain directed at those of us who have lived with a tiny but powerful bacillus. There have been massacres by gun fire, forced abortions, sterilizations, banishment, and

forced divorce, separation from children and spouses, incarceration without due process, segregated burials, brutal administrators, and uncensored experiments. Among many other indignities, those diagnosed with leprosy have been refused access to public transport, denial of the right to vote and own property. Persons with leprosy have been placed on islands with treacherous waters making escape impossible. They have been isolated in jungles, on top of mountains surrounded by stone walls reminiscent of the Great Wall of China, archaic buildings surrounded by rough terrain, or in camps with barbed wire and armed guards. They have been forced to live in areas across raging rivers with no bridge. All of this isolation has been done in the name of alleged safety from those not understanding the grief they have caused.

These humiliations, along with the chronic use of the “four letter” word spelled *repel* in reverse has given fuel to the spread of stigma. However, in the midst of the mistreatment, there has always been activism. There are thousands of unknown heroes from the past whom we suspect have been strong advocates for the humane treatment of persons experiencing leprosy. In more contemporary times, hundreds forcibly institutionalized at the national leprosarium (called by many names throughout its 105 history) in Carville, Louisiana did their own advocacy from within the walls of the 350 acre facility.

Some of their actions have included but not limited to: refusal to wear prison like attire; protest against internal segregation by sex; and prohibition of the sale of Coca Cola at the Patient’s Canteen after the local distributor refused to recycle bottles from the facility. Carville patients sought to end injustices by at least one of the administrators by forcing the federal government to remove the person from his post. Other patient led changes included adding a school for minors, allowing patients to work, establish a Patient’s Federation, Lions Club and Mexican Club. Patients efforts have allowed families to visit, discarded the practice of segregated chalices during communion at the Catholic Chapel, and stopped the “sterilization” of outgoing and incoming mail to patients.

In 1931 patient activism gave birth to an international publication, *The STAR*. The *STAR*’s motto “Radiating the light of truth about Hansen’s disease” reflects the vision of the publication’s first editor, which continues to have relevance today. The publication was written, printed and distributed by patients. While it as a patient led activity, it has received the steadfast support from the 40 & 8, a veteran’s organization formed after WW I. One of the first gifts from the 40 & 8 was funding to purchase a brand new printing press in 1943. An on-going support is the publication and distribution of *The STAR* throughout the globe.

*The STAR* was the first publication to include articles on both HD related research and human interest stories. Up until 1999 it mailed out internationally on a monthly basis and now on a bi-annual basis.

*The STAR* became the first publication that was “sneaked” into hundreds of leprosarium throughout the world by medical staff sensitive to the condition of those involuntarily admitted to far away and forgotten facilities.

*The STAR* was the first “news” read by millions at these isolated facilities. It was the way many individuals first learned about the “miracle” drug Dapsone. Dapsone is still the medication of choice in the treatment of HD.

*The STAR* contributed to patient empowerment as millions of brothers and sisters started demanding access to Dapsone, though for some it did not become available until decades after first prescribed at Carville.

As a patient publication *The STAR* has committed to always have a person who has experienced HD to serve as

its Editor. The Editors have included: Stanley Stein, Louis Boudreaux, Emanuel Faria, Ray Elwood, Abel Aparicio, Willie Kikuchi, Simeon Peterson, and now Jose Ramirez, Jr.

These editors all lived in the Carville facility which is now occupied by the Louisiana National Guard. It is and was surrounded by the one mile wide Mississippi River and swamps with only one road going to and leaving the leprosarium. Our brothers and sisters who lived in Carville shared the isolation experienced by so many others across the globe. Yet despite the isolation, persons experiencing HD living in Europe, South America, Asia and Africa have become strong advocates, fighting for basic human rights and the cessation of pejorative terminology that has facilitated the spread of horrible images and the continuation of stigma. Ironically, the persistence of isolation, discrimination and stigma against those of us who have experienced leprosy has also resurrected the strength of advocates who have become local celebrities and fight with words to kill the dragon and its siblings of stigma.

For the most part forced isolation has ended, and slowly these prisons have become a part of history. Slowly these facilities have become part of history. However, the stigma and images of yesteryear have continued to survive. Therefore, major efforts are underway to restore and maintain many of these unique facilities, not to re-introduction institutionalization but rather as national heritages that represent not just the injustices which must not be forgotten, but for capturing the strength of persons who have experienced leprosy who have fought against such injustices. In some countries such as in Japan and Spain these facilities have been blended into the broader community. These battles against stigma represent over 50 generations of families going back to pre-biblical times.

In 1994, IDEA (Integration, Dignity and Economic Advancement) was born when persons experiencing leprosy, inspired by the millions who had come before them, decided that another effort to fight via education was timely. IDEA has become an international organization committed to the inclusion of person with Hansen's disease in all areas of society, to promote human rights and empowerment, and end discrimination and stigma. IDEA is the only organization of persons who have experienced HD with an international membership of 22 chapters in five continents. Throughout the last 24 years, IDEA members have joined forces with other organizations with the compassion to assist in meeting the needs of other members.

Their efforts have included the purchase of a machine to make special footwear and research to identify and train volunteers to educate those not yet able or willing to receive appropriate treatment after a diagnosis. IDEA members have conducted oral histories in an effort to save the voice and memories of those who have experienced leprosy. They have made presentations at all levels to educate as many persons as possible about leprosy and dispel the myths surrounding it. The organization provide scholarships to families, trains and empowers members, and advocates for their inclusion on boards and other venues related to policy and implementation. It educates the youth of the world and provides financial support to those wishing to enhance their skills in their chosen profession. The self-esteem of members is enhanced by their participation in events celebrating World Leprosy Day or International Day of Dignity and Respect. Finally IDEA provides counseling to those who were traumatized when initially diagnosed and believe that they are being punished by their God.

IDEA will celebrate its 25th Anniversary at the 2019 International Congress on Leprosy in Manila, Philippines.



The organization's motto is "The language of IDEA is INCLUSION." This has been evident in the numerous awards bestowed on many of its members at an international level, and in their respective communities.

A more recent effort to address stigma, research and innovations in leprosy control programs has been the creation of the Global Partnership for Zero Leprosy. The goal of the organization is zero leprosy: no discrimination, no disease, and no disability. This partnership, first discussed at the International Leprosy Congress in 2016 at Beijing, China, has started to gain much momentum. The initial plan was to address a possible collaborative effort by the Novartis Foundation from Switzerland. Experts from Novartis, The World Health Organization (WHO), IDEA, academia, ILEP, NTD, ICL and many others have embarked on a journey that hopefully will help to lessen stigma and enhance early diagnosis and treatment.

The three ZEROS of the partnership include education against stigma, research designed to match the roadmap related to leprosy developed by WHO's Neglected Tropical Diseases related to leprosy (participants and sub-groups have global representation), and "operational excellence." The latter refers to the development, use, monitoring and evaluation of best practices in national leprosy control programs.

As is the case with similar efforts, there is much discussion about the balance of "getting more persons with HD involved" in the Global Partnership and actually accomplishing such. As a result we in the world of Hansen's disease continue to experience bumps on the road to the lessening of stigma. However, we are strong advocates and do not easily give up. After all we have millions who came before us to look up to.

## **SPECIAL RAPPORTEUR ON LEPROSY**

**By José Ramirez, Jr,**

In November of 2017 Dr. Alice Cruz was appointed by the United Nations Human Rights Council as the Special Rapporteur on Leprosy. Since that time she has met with numerous national and international organizations in an effort to gain insight into the battles against stigma and efforts to enhance medical diagnosis and care.

Some immediate actions she had taken include the education of world leaders on their use of terminology and inappropriate use of metaphors related to leprosy. Dr. Cruz has strongly urged these leaders to not use negative symbolisms which project horrible mental images to the public. Some of these leaders include the President of France, Emmanuel Macron, Italy's deputy prime minister Luigi Di Maio, and Portuguese prime minister Antonio Costa.

On a more long term basis she has developed questionnaires designed to collect data regarding the "social, economic, cultural and political dimensions of leprosy." Dr. Cruz has an email at [srleprosy@ohchr.org](mailto:srleprosy@ohchr.org) and a website [www.ohchr.org/EN/Issues/Pages/LeprosyIndex.aspx](http://www.ohchr.org/EN/Issues/Pages/LeprosyIndex.aspx). The STAR has invited Dr. Cruz to be a regular contributor to the forthcoming issues and thus we look forward to her comments.

## We Remember...Lest We Forget

By Tom Adams, National Director Carville STAR Program

A recent article in my local newspaper informed readers of a grant to the National World War II Museum in nearby New Orleans. The \$2 million grant will be used to expand Holocaust education programs at the museum. The founder and chairman of the philanthropic sponsor of the grant states "The new Holocaust Education Program is critical as Americans are remembering less and less about the war and the lessons of the Holocaust."

Indeed, we have a tendency to remember "less and less" of our history and the lessons it has taught us. While I in no way equate the magnitude of the horror and carnage of the Holocaust to patient experiences at Carville, periods of Carville's history were tainted by extreme mistreatment of its patient population that we ought not to ever forget. By remembering such negative events of our past, we will hopefully be responsible enough to never repeat them.

Negative patient experiences are particularly characteristic of the early history of Carville - loss of patient identity upon admission when assigned a number and given a "new" name; separation from family and friends and no communication with them; a permanent sentence of quarantine to a location rimmed with barbed wire and guards; and disenfranchisement - to name some. Similarly trying experiences were commonplace among Hansen's Disease (HD) patients at locations throughout the world. May we never again inflict such hardships upon "victims" of any disease. Fortunately, over time the United States Public Health Service (USPHS) Hospital at Carville evolved into a world renown institution that paved the way for cure of HD and pioneered quality rehabilitative services. Since the 1940's, 40&8 has been actively involved at Carville, especially in helping reduce or reverse the stigma associated with HD through our publication, *The STAR*.

While the Public Health Service Hospital at Carville is no more, we are blessed to have a museum at Carville (The National Hansen's Disease Museum) to remind us of the negative and positive aspects of life as a Carville patient. It is the museum and the historic district surrounding the museum that are the focus of much of the activity of 40&8's Carville STAR Program. Support for the museum is where most of the funds from donations and pin sales are directed. Though the museum is limited in floor space, La Societè is honored by two prominent exhibits that tout our organization and inform visitors of our history at Carville. Visitors from all over the world find their way to the museum and through the two exhibits are introduced to the 40&8, its history, membership requirements, and programs.

The phrase "lest we forget" is credited to Rudyard Kipling who pinned the poem "Recessional," written for Queen Victoria's Jubilee in 1897. Kipling took the phrase from Deuteronomy 6:12 (Then beware lest thou forget the Lord, which brought thee forth out of the land of Egypt, from the house of bondage). The Carville museum records the history of how the United States managed a patient population that was uniquely scorned and maligned solely because they were afflicted with a disease state unlike any other in our history. Today our country offers easy access to drug therapy and rehabilitation for HD patients at clinics affiliated with the National Hansen's Disease Program. How quickly we can forget the journey that led to accessible care. The Carville museum is the needed educational reminder - "lest we forget" both the patient suffering and the revolutionary advances in therapy identified with Carville.

The National Hansen's Disease Museum is located at 5440 Point Clair Road, Carville, LA 70721. The museum is open 10:00 AM until 4:00 PM, Tuesday through Saturday and is closed on Federal Holidays.



One museum exhibit features this mid- 1940's photograph of the 40&8 presenting The STAR printing press to Medical Officer in Charge Dr. Frederick Johansen.

## TRANSITION TO CHANGE

By José Ramirez, Jr. Editor

This issue is dedicated to Simeon Peterson, aka as Mr. Pete, Dr. Pete and Ambassador Peterson. His names are so relevant because he represented so many things to so many individuals, but more important he represented the souls of thousands who went through the “Gates of Carville” on the way to the “Gates of Heaven.” Pete will always be remembered as a unique individual who brought joy to all who met him, even for a moment. Pete passed away in November of 2017

With the passing of Mr. Pete also means the “moving on” of two members of the Editorial Board, Irma Guerra and Elizabeth Schnexyder. Their contributions throughout the last two decades represent invaluable time and effort to carry the torch left behind by Stanley Stein, “Radiating the light of truth about Hansen’s disease.” I am extremely grateful for their dedication to The STAR and guidance with stories. Thanks, Merci, Gracias.

Another change is updating the “purpose” of The STAR found on the right hand side column of page 2. The purpose will now replace the original second and add a third: 1) Promote an educated public opinion of Hansen’s disease; 2) Serve as advocate for those who have experienced or been impacted (family members) by Hansen’s disease; and 3) Foster self-empowerment of those who have experienced HD. For some, advocacy translates to a physical presence, but advocacy from The STAR is intended to reflect an influence on how the reader(s) view the World of Leprosy, which should be in a positive and meaningful manner. Persons who have experienced HD are brothers, sisters, mothers, fathers, sons, daughters and much more.

The two remaining Editorial Board members are the new Editor, José Ramirez, Jr, a licensed social worker living in Houston, Texas, and Dr. David Scollard who formerly served as Director of the National HD Program in Baton Rouge, LA. These two are now joined by an excellent group of dedicated individuals who have a connection to HD. Two represent, for the first time on the Board, family members of persons who have experienced HD and thus impacted by HD. They are Dr. Claire Manes a retired university professor and my daughter who is an Assistant District Attorney. Other “newbies” include Dr. Thomas Adams, a retired pharmacist; Mary O’Friel of IDEA; and Mike Woods, former National Directeur of The STAR for the 40&8.

Mr. Adams who now serves as Carville STAR National Directeur for the 40&8 is joined by a wonderful Carville STAR Committee. The committee members are Ernie Cooper, Steve Villegas, Dennis Engdahl, Ron Diebold, Tom Emerson, Hank Kwiatkowski and Gordon L. Foley.

## Thomas R. (Tom) Adams, M.S. Pharm., RPh Joins The Star Editorial

- 29 years of service in United States Air Force, serving as pharmacist, medical software developer/implementer, and hospital commander
- Post-retirement years (since 1999)
- 13 years as pharmacist at Federally Qualified Health Center, Mississippi Gulf Coast
- Volunteer Medical Director for Honor Flights, flying over 600 World War II veterans to Washington to visit their Memorial
- 18 year affiliation (volunteer) with St Vincent de Paul Community Pharmacy, now volunteer Pharmacist-In-Charge
- providing 30,000 free prescriptions annually to those in need along the Mississippi Gulf Coast
- preceptor/mentor to pharmacy students, guiding them in how to fulfill drug therapy to an indigent population
- Member Board of Directors of DREAM Program - to serving those with disabilities by providing athletic and art opportunities at no cost to program participants
- Member Ocean Spings Chorale with 2018 performances in Austria and Italy
- Selected Directeur Carville STAR at 99th Promenade Nationale in 2018



*Editorial Board Service - I am pleased to be on the Editorial Board of The STAR. As Directeur of 40&8 Carville STAR Program, my goal is to insure that 40&8 leadership and members understand the relevance of the Program. The STAR is critical to the identity of the Program and I desire for it to be a quality publication fulfilling its stated purpose. I believe my role to be liaison between the Board and 40&8 leadership - being a conduit for communication between the two. I have contributed articles to the STAR and as Directeur intend to provide regular input to The STAR to inform 40&8 members of our activities at Carville. For years I have had a passion for learning about HD, from a scientific and historical/social viewpoint. I have read extensively on the subject of HD. I have an extensive philatelic collection on exhibit at the National Hansen's Disease Museum. (The collection represents years of effort to garner worldwide philatelic material concerning HD.) I am a graduate of the National Hansen's Disease Program's Seminar for Healthcare Professionals. I covet my board membership and look forward to board service.*

## Claire Manes PhD Joins The Star Editorial Board

Claire Manes is a retired educator who has earned a bachelor's degree in education, a master's degree in theology, and a doctorate in English. However, her lifelong passion has been searching for her grandfather, Edmond G. Landry, aka Gabe Michael, case # 300 in the United States Public Health Services Hospital #66, Carville, Louisiana.

As a young girl, she learned that her grandfather had leprosy and died in Carville, but she also absorbed the silence from her elders that surrounded him. Years later, when letters from Edmond to his family were discovered, Claire returned to college to gain scholarship to tell her grandfather's story. After earning her doctorate from the University of Louisiana at Lafayette, Claire authored the book *Out of the Shadow of Leprosy: the Carville Letters and Stories of the Landry Family*. She says

of this book, "This is what I was meant to do." She continues to increase awareness about Hansen's disease and advocates for an end to stigma for those with HD as well as other feared and misunderstood conditions.



## Mike Wood BBA, AA Joins The Star Editorial Board

Graduated The University of North Carolina at Chapel Hill with a BBA degree in Business Administration, AA degree in Economics from the Keenan- Finley School of Business at UNC.

Served in The United States Marine Corps 1968–71, served one tour in Vietnam with the 1<sup>st</sup> Recon Battalion. Military Honors received were Bronze Star with V, Purple Heart, Marine Corps Combat Action Ribbon, National Defense Medal, Viet Nam Service Medal, RVN Gallantry Cross with Palm, Presidential Unit Citation, Viet Nam Campaign Medal, USMC Parachutist, Rifle Expert and Pistol Expert Badges. Was Honorably Discharged in 1971.

Ha been a member of the Forty and Eight for 30 years and has served as the Nationale Carville Star Directeur and Chef de Chemin de Fer and is now serving as Nationale Advocat.

He makes his home in Newnan, GA with his wife of 34 years Sandy.



## Mary O’Friel Joins The Star Editorial Board

Ms. O’Friel is currently the International Coordinator and formerly the Program Facilitator for the International Association for Integration, Dignity and Economic Advancement, where for the last 20 years she provides program support to IDEA Branches in their human rights and advocacy efforts for persons affected by Hansen’s disease/leprosy. In this capacity she helped draft the Convention on the Human Rights of Persons Affected by Leprosy (Istanbul, Turkey, 2008), which served as IDEA’s reference point when advising on the development of the United Nations Principals and Guidelines on Elimination of Discrimination Against Persons Affected by Leprosy and Their Family Members. She has traveled on behalf of IDEA to support empowerment and women’s workshops, development of new branches, and facilitation of conferences in Brazil, Ethiopia, Kenya, Nigeria, South Africa, Nepal, India, China, South Korea, Belgium, England, France, New York and Washington, D.C.

She also supports the Secretariat for the International Coalition for Historic Sites of Exclusion and Resistance, coordinating the Hansen’s Disease/leprosy heritage efforts for the Coalition, including managing the Cultural Heritage Assessment process; building a database of heritage sites; and identifying and liaising with individuals and organizations integral to the heritage process.

Ms. O’Friel holds a Masters in Health Care Administration and has worked in NGO management for over 30 years, including serving as Executive Director of Hui Hoa Aloha, The Hawai’i Hansen’s Disease Association.

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## Erika Ramirez Joins The Star Editorial Board

Erika Ramirez is a prosecutor with the Harris County District Attorney's Office in Houston, Texas. Her father, Jose P. Ramirez, has worked as an advo-



cate for persons affected by Hansen's disease her entire life. She has joined him on some of his advocacy trips to the United Nations in New York City and Vienna, Austria. Erika and her brother, JR Ramirez, hope to be a voice for the family members of those affected by Hansen's.

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PH: (404) 686-5885  
Public Health Nurse: Jennifer Breiman, RN  
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### **BOSTON HD CLINIC**

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### **CHICAGO HD CLINIC**

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Public Health Nurse Yusuf Adegoke, RN  
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### **LOS ANGELES HD CLINIC**

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### **MIAMI HD CLINIC**

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### **PHOENIX HD CLINIC**

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### **SPRINGDALE HD CLINIC**

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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, 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 Amanoer 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 2016 there were 216,108 new HD cases registered from 145 countries according to World Health Organization official figures. The countries with the highest number of new diagnoses are India, Brazil and Indonesia followed by some of the African nations. More than half of all new cases of leprosy are diagnosed in India.

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. 178 new cases were reported in the U.S. in 2015. Most of the new cases were reported in Arkansas, California, Florida, Hawaii, Louisiana, New York, and Texas.

### 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 dapson, 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](http://www.hrsa.gov/hansens)