

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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Above: Photo Courtesy of the Ramirez family.

Generations of people have worked within and outside the HD community to ensure respect for those impacted by the disease. As a young man in Carville Ray Elwood achieved the rank of Eagle Scout, a feat achieved by only a few.

More than fifty years later, JR Ramirez, a young man impacted by HD, brings respect and love to HD survivors in Ukraine during more peaceful times.

Right: Photo Courtesy Johnny Harmon and the National Hansen's Disease Museum



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Founder - Editor, 1941 - 1967

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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.

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," or when it is used as a medical term. We dislike the word "leprosy" intensely, but we dislike the practice of censorship even more. Furthermore "The Star endorses Section II, 13c of the United Nations Principals and Guidelines addressing discrimination of persons who have experienced Hansen's disease, that encourages the media to portray persons who have experienced the disease using 'dignified images and terminology.' "

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Ukraine: A Lesson in Resilience

by Jose Roberto (JR) Ramirez

I woke up on the morning of February 24, 2022 to news that saddened my heart. My Twitter feed provided small glimpses into what has become a months-long brutal assault on the Ukrainian people. While taking in the multiple images of suffering and destruction, I couldn't help but recall the memories of my visit to Ukraine more than a decade ago.

In 2007, my Dad (Jose Ramirez, Jr.) asked me to join him on a trip to Kutschurgan, Ukraine to conduct oral histories of persons with Hansen's disease (HD). These oral histories were recorded and archived as a resource for researchers working on stigma. The trip was sponsored by IDEA, the International Association for Integration, Dignity and Economic Advancement. IDEA is an international organization of persons who have experienced HD.

My parents had previously journeyed to Fontilles, Spain to conduct oral histories of persons with HD isolated on the top of a huge hill with orange groves engulfing the side and a view of the Mediterranean Sea. This “leprosy hospital” was surrounded by a cinder block wall 11 feet high, and two feet thick and two miles long. It took seven years to build and had guard towers with small openings for rifles. The purpose was to “prevent patient escape.”



Caring for the residents left to right
Ludmilla, nurse, Dr. Naumov
and Jose Ramirez, Jr.



JR Ramirez and Marta (translator) on the road to the HD Hospital

Fontilles, opened in 1909, was home to many elderly persons who were sent there simply because they were diagnosed with HD. Many had been there for decades. Mom and dad, fluent in Spanish, and having visited the community previously, were invited to revisit and complete oral histories using a small video camera. The previous visit was a week-long conference with persons like my dad who had experienced HD, and persons like my mom, impacted by HD. Those oral histories are now in archives used by researchers working on preserving and remembering the history of people who have experienced HD.

Kutschurgan had a small community of persons with HD, long defunded by the government since, according to WHO (World Health Organization), HD did not exist

in Ukraine. The persons living at Kutschurgan had been abandoned by their families and lived in small cottages tended by a family of caregivers. A cemetery on the property, overgrown in weeds, was a reminder of the many who had died separated from their families.

Our two local guides helped with translation for my Dad's interviews. Leonard (a Ukrainian priest) translated the oral histories from Russian to Hungarian. Marta (from Hungary) translated from Hungarian to English. Not knowing what to expect, I could only recall my Dad's experiences in Carville, Louisiana, and physical and emotional suffering he experienced as a result of the disease. I recall one older gentleman at Kurschurgan sharing that his eyes were in such pain as a result of the nerve damage brought on by HD, that he wanted to pull his eyeballs out of his socket. He also shared his surviving a Nazi concentration camp by playing dead underneath a pile of bodies.



**Valentina and Sergey Rolinichenko among the caregivers at the facility.
Pictures courtesy of the Ramirez family**

Growing up in the warmer Texas climate, the cold weather in Ukraine was unlike any I had previously experienced. I recall that the cold evenings made me shiver, and my hands were numbed by the icy wind. The dark, rich soil of the fertile land could be seen for miles. Our hotel was a few blocks away from the Black Sea in the port city of Odessa. We took in the local historical sights and visited a restaurant that entertained us with live Ukrainian music and introduced us to goulash.

While many of the stories were sad, I also was heartened with stories of love, strength, and dignity. The resilience displayed by the residents was inspirational -- I could only hope and pray to mimic one-tenth of the grit possessed by the interviewees if I were placed in a similar situation. The residents were assisted by the caregivers, who were a husband and wife team (Valentina and Sergey). Their warm, steadfast presence made the place feel like home -- that warmth radiated within the living quarters and was palpable.



Maria Mirchuva and Che Vanson among those who shared stories of their lives

As I write this article months after the start of the invasion, I hear recent news of a grandmother, mother, and three month old baby losing their lives via a missile attack in Odessa. I think back to the residents of Kutschurgan that I had the privilege to meet, having heard their stories that are unlike any other in the world. I can only hope that my efforts to pass on their stories will continue their legacy of hope -- hope is what the people of Ukraine (and the rest of the world) need right now.

Remembering Ray Elwood—A Good Man with a Big Heart

by Claire Manes

Ray Elwood's heart gave out on November 29, 2021. He was 89 years old. It is not surprising that his heart wore out. He was a man whose time and heart were shared generously with others—his community in Carville, his business associates and clerks in Texas, and above all his Texas and Louisiana family.

As a young boy on the beaches of Key West, Florida, he had ambitions to be a doctor. Hansen's disease changed that dream but it did not destroy his heart for service. In 1948 when Ray was fifteen, he and several other family members were confined in Carville, Louisiana. It was the first of his two periods of confinement and his initial introduction to the Carville community. Like so many others diagnosed with HD the reality of confinement upended his plans and challenged his spirit and determination, but his heart prevailed.

At the time the Carville community had other young people in residence and they became a community within a community, engaged in many activities available to them: pool, badminton, golf, and tennis. Perhaps the sport that most stole his heart was softball. He was a member of the Point Clair Indians team that won the River City League championship against powerful teams in the region. The Indians were the only racially and culturally integrated team in the league and the one with complete home field advantage.

Like other young men he pushed the boundaries on occasion—swimming in Lake Johanssen (a forbidden practice) and escaping through the hole in the fence for evenings in Baton Rouge and New Orleans. Years later he recounted one such incident to Marcia Gaudet. The account as he related it is in her book *Carville: Remembering Leprosy in America*. Ray remembered a particular evening out in Baton Rouge. Before the young men returned to Carville, they stopped at the bus terminal for coffee. A patrolman questioned them and was suspicious of the multiple unsubstantiated stories they told. As he called for backup, his partner began frisking the youth.

When the backup arrived, one of the police recognized Ray and called out, "Ray is that you?" Then he said, 'Ah I know these guys—we played ball with them in the River League. They're okay—they're from the leprosy hospital.' The detective who had been frisking us jumped back five feet and began rubbing his hands on his clothes. The detective who knew us started laughing and put his arms around us and said, 'Don't worry they're safe.'" (67-68) Recognition and the River League saved them.

Ray approached his first stay in Carville with serious intent as well. As a Boy Scout he earned the rank of Eagle Scout, an achievement of great pride to him even in later life. The Scout troop also provided him with his first job for *The Star*, assembling the magazine for distribution. Later he typed articles for print and took dictation from Stanley Stein. As Ray related it. "I knew how to type but I had never taken dictation before. It was an experience that I have never forgotten. The man was using words that I had never heard before. After leaving his office I spent half of the day looking up the words in the dictionary." (Elwood)



As editor of *The Star* Ray Elwood connected with national and international personnel involved in radiating the truth about Hansen's disease.

Photo courtesy of the National Hansen's disease museum



Tommy Sanders and Ray Elwood, members of the first Boy Scout troop at Carville. Ray earned the honor of Eagle Scout, the highest honor in scouting. Photo by Johnny Harmon

With treatment and successful negative tests, Ray left Carville in 1953 marrying and moving to Texas. He and his wife were parents to four children and for 16 years Ray managed a standoff with HD. As a husband and parent, he worked hard to provide for his family and maintain his health. For 16 years the détente worked, but then HD had its way with Ray once again. A few small spots on his chest and a reactive episode sent him back to Carville not as a boy but as a man who left behind a cherished family and a life outside the fence. (Corson)

Bereft of his wife and children Ray gave himself over to his fellow patients and his “family” in The Star office. From his previous service on the journal, he knew all aspects of this major publication and became the “Man in Demand.” (Corson) Stanley Stein had died in 1967 and Louis Boudreaux, editor and the other Star pioneer, recruited Ray to help with the paper and later to become the third managing editor of the international publication.

The Star was not his only passion, however. He soon began spending his noon hour visiting Julia Dobbs, the former patient now the Carville school’s teacher. After a year the two, both divorced from other spouses, married, and Ray’s heart expanded to embrace both Julia’s five children and his own four in Texas. On one occasion he loaded all nine children in a Toyota van for a trip to Six Flags—an act that could surely earn him the title “Father of the Year.” (Corson)

Family clearly was Ray’s first love as he always cared for his children and took pains to protect them from HD and to shield them from the stigma the condition could invite. His heart, however, was big enough to also encompass the needs of his “brothers and sisters” in Carville. He crusaded for HD awareness as editor of The Star and engaged in civic activities through the Point Clair Lions Club. His own roots were Bahamian, but for a time he was a member of the Carville Mexican club as proxy for Julia who as a federal employee could not participate in the organization.

He also exercised political clout as a member and president of the Patients’ Federation, the strong political arm for the patients. As the patient count dropped the federal government began to consider closing the Carville hospital and residences. Ray and others in the organization, sensitive to the financial needs of younger patients and the health care needs of those infirmed or unwilling to leave, began negotiations with United States Representative Richard Baker and the Public Health System. Their efforts assured annual stipends and medical care for those who left and comfort and care for long time patients who remained. (Elwood)

Ray and Julia opted to leave Carville and move near San Antonio where they would be near his “Texas family.” Frequent visits to Louisiana assured regular contact with their Louisiana family. For years their life together sustained them as it was built on mutual love and respect and an understanding of the pain and challenges known best by HD survivors. News-filled letters to friends and family documented a full life together. Ray’s final acts of love were the attention and care he gave Julia when she could no longer care for herself. Those who knew Ray called him a leader, an achiever, (Corson) a kind man and peace maker (Gaudet)—all terms easily summed up with the words “big heart.”

Rest in Peace, Ray. You loved much and well.

(Author’s note: I met Ray only once but his loving embrace is a gift I recall to this day.)

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The Forty and Eight (Not Just Another Veterans' Organization)

by Tom Adams, R.Ph.

Every issue of The STAR includes a "Get to Know the Forty and Eight" section with some limited information about the origin and mission of this organization to which I proudly belong. Though formed in 1920 as an arm of The American Legion, the Forty & Eight became an independent and separately incorporated veterans organization in 1960. Membership is offered by invitation to honorably discharged veterans and honorably serving members of the United States Armed Forces.

How does the Forty and Eight differ from other veterans organizations? Its members are "voyageurs" who experience an initiatory rite of passage that includes both levity and moments of thought-provoking reflection. Though its mission is serious, its get-togethers at local, state, and national levels are intentionally light-hearted. (The local level is a "Locale," comprised of voyageurs of a city, county or counties, or region. Locales form a "Grand," a state-wide organization.) Founders of the Forty and Eight believed that a sense of humor better prepares us for disasters and the most difficult of times.

Though having fun is essential, the real fun and satisfaction of a Forty and Eight voyageur comes from service - service to veterans and to members of the community who are in need. Voyageurs of Forty and Eight commit to regular attendance at meetings (Promenades) and therefore actively contribute to the organization's mission to serve. Detailed information about each Forty and Eight program is found on its webpage <https://www.fortyandeight.org/>. The following recounts some of my first-hand experiences and knowledge of these programs garnered from 16 years of membership.

Child Welfare: Voyageurs founded a Child Welfare Program in 1923 to ease the pain and suffering of those children whose fathers never returned or who were unable to care for their needs after World War I. Today, this program has grown to include children with emergent needs identified by Locales.

Youth Sports: The motto of this program is "No athlete shall stay home for lack of funds." Through this program financial assistance is provided to individual athletes or teams who lack the funds required to attend and participate in amateur sports programs. This program encompasses all amateur sports programs for youth from 7 to 20 years of age. In my Locale (Gulf Coast Mississippi), we fund uniform t-shirts for one team of athletes with disabilities that compete in year-round sports - basketball, flag football, and softball. Thanks to our support, these athletes are able to participate without cost.

Nurses Training: This is a program that is just as relevant today as it was in 1945 when it was begun in response to an acute shortage of nurses in the United States. Scholarships are awarded by Locales and through a scholarship fund managed by National Forty and Eight. Since 1955 over \$34 million in scholarships has aided over 52 thousand student nurses in achieving an undergraduate degree and another 21 thousand a graduate degree. In my Locale, we seek to be aid of last resort to student nurses in financial distress. As such, we help single parents and those who have exhausted other forms of aid (loans and grants). I have witnessed the graduation of many students who would have been in jeopardy without our assistance. (One such nurse cared for my spouse after a knee replacement!)

Americanism: As the website states, this program is popular among voyageurs because it reflects a strong commitment to the American way of life - our history and law and order. The Flags for First Graders entails visits to schools for in-person programs on how to care for, display, and respect the flag of our country. Most

of these programs include supplying every first-grader with a small flag to take home. My Gulf Coast Mississippi Locale visits surrounding school districts and presents our program to over 2,000 first graders, giving each a small flag. Americanism also sponsors the Forty and Eight's annual awards to the Law Officer of the Year and Hero of the Year.

VAVS: In brief, the Veterans Affairs Voluntary Service (VAVS) program provides a link with Veterans Administration Medical Center (VAMC) to assist veterans and promote their understanding of Veterans Administration (VA) policies, procedures, and benefits. My Locale takes advantage of VAVS's "Keep the Wheelchairs Rolling" program that has funded projects, equipment or comfort and convenience items needed by hospitalized veterans at our nearby VA Medical Center - needs of patients that are not fulfilled by the VA.

POW/MIA: This program maintains a fund to provide scholarships for Prisoners of War (POW) , and the descendents (spouses, children, grandchildren, or great grandchildren) of POWs or the Missing in Action (MIAs).

Carville Star: Known for funding the publication and distribution of this "newspaper," this program is much more. Carville Star funds projects and equipment for the museum and the Carville Historic District (the grounds of Carville) through the sale of annual pins and the promotion of special projects. Support for Carville is tightly bound into history and tradition of the Forty and Eight. No other veterans' organization has as a declared mission to disseminate information to promote understanding of a disease, thereby reducing stigma of the disease. Based on her recent interface with voyageurs, Claire Manes, author and my colleague as a Board Member of The STAR, offers her assessment of how voyageurs view the Carville Star Program:

Like other readers of The Star I have heeded the invitation to get to know the 40&8. However in February of this year I met members of the organization. I had the opportunity to meet voyageurs from Kansas, Mississippi, Florida, Tennessee, and North Carolina in New Iberia, Louisiana, for their annual meeting, usually held in Lafayette, Louisiana, with an important pilgrimage to Carville, Louisiana. Since Carville was still closed due to Covid, Tom Adams, 40&8's Directeur of the Carville Star Program invited me to speak to the group gathered in New Iberia. That was the day I truly got to know the 40&8.

I have had the opportunity to speak to diverse groups about Carville, Hansen's disease and/or my family's connection with both. These groups have always been interested and respectful. They are there to learn and ask questions. The 40&8 members were different. I had the feeling that I was speaking about "our" Carville. These men and women are part of a long line of volunteers for whom Carville is not a project, but a passion. They are not simply an organization; they are a community united by their shared military service, their membership in the 40&8, and their service to others including Carville.

Since 1941 members of the organization have worked with and for Carville. They have donated funds and sweat equity to The Star, the museum, and the Carville Historic District. They have spoken about and educated on Hansen's disease. They know the truth about the condition and they proudly share that knowledge with others.

I am honored to know not just the organization but the men and women of it. I consider them godparents, ambassadors of Carville, outside the fence, but just as much a part of the Carville story as those who willingly and unwillingly resided there as staff and residents.

The Forty and Eight is a unique veterans' organization, with a place for every qualifying veteran or active duty member who believes in service to their community and nation.

A Personal Journey With Thalidomide

by Jose Ramirez, Jr.

A recent trivia on U.S. Presidents stated that on “October 10, 1962, President John F. Kennedy signed an amendment to the Federal Food, Drug and Cosmetic Act.” This amendment, signed 60 years ago, made it mandatory for pharmaceutical companies to “prove” that their products were “safe and effective prior to marketing.” The Act was in response to the thalidomide birth defect crisis.

Thalidomide was originally used as an over-the-counter medication in the 1950s. Strongly marketed in Germany as a “miracle drug,” it was used to prevent anxiety and morning sickness, as well as a sedative to enhance sleep. Unfortunately, thalidomide became the Titanic of medicines-----“an unqualified belief in safety and invincibility.”

This miracle blue pill caused worldwide panic as pregnant women started taking the pill for morning sickness. The medication caused birth defects, including babies born without limbs, severe speech impediments and cognitive impairments. However, the initial panic did not immediately result in stoppage of its sale.

In the early 1960’s, Dr. Jacob Sheskin, a Hansen’s disease (HD) expert in Israel commenced administering thalidomide to patients experiencing nausea and insomnia due to ENL (Erythema Nodosum Leprosum). This was before it was known that the drug caused birth defects. The scientific community formally heard about the “positives” of thalidomide at the VIII International Leprosy Congress. Once the teratogenicity was recognized, it was banned worldwide.....except for ENL! ENL is a “reaction” felt by persons with HD manifesting as a general malaise with fevers, nerve pain and nodules throughout the body. A “reaction” is simply known as an inflammatory disorder. The control of ENL, however, has not been so simple.

Up until my diagnosis at Mercy Hospital in Laredo, Texas, I had unknowingly experienced episodes of reactions intermittently for many years. My ENL, as it was for others with HD, was chronically painful, caused nodules throughout the body, and nodules became bloody which caused scarring. Doctors in Laredo, San Antonio, Texas, and Monterrey, Mexico were unable to explain or diagnose my illness. The diagnosis finally occurred when a biopsy of one of my nodules was sent to the Center for Disease Control (CDC) in Atlanta, Georgia. When the HD diagnosis was relayed to the Laredo hospital, and spread among the staff, I was immediately placed in “isolation.” Within 24 hours, the Director of the Texas Health Department was at my bedside to inform me of my diagnosis. He dryly added that I would be transferred to “Carville” the next day as “that is the only place you can receive treatment.”

The trip to Carville started the next day, in a hearse, at 4:30 am. My parents, Jose P. and Rosa, were informed by the local providers of ambulance service that “ambulances are for the living and hearses for the dead.” The Sisters of Mercy who paid for the transport were aghast, but the trip needed to get done. One of my



Jose Ramirez was admitted to Carville in 1968 with this bag containing only minimal clothing.

“Photograph courtesy of National Hansen’s Disease Museum, Carville, LA”

older sisters, Raquel, administered morphine during the long trip in order to soothe my pain. Magdalena Santos, my girlfriend, rode in the hearse with me most of the trip. My parents and sister followed in an old Chevrolet.

The journey to Carville in February 1968 was believed by family, as well as others, to mean that my destiny was death. This belief was supported by a priest assigned to the Laredo hospital as he administered the last rites while I was slowly pushed into the hearse, decorated inside with curtains. My family's only knowledge of HD was about the alleged "punishment from God." So, my mother believed that I would not return to Laredo alive. She packed only a small bag containing one pair of jeans, one t-shirt, one piece of underwear and one pair of socks. No shoes.

During the last leg of the trip, we traveled in a moonless night following a narrow road hugging the Mississippi River levees. The travel was 20 miles past the gates of Louisiana State University (LSU) in Baton Rouge, Louisiana. We arrived at another gate, guarded by security officers. By then it was 11:30 pm, and we were exhausted. I was placed in the equivalent of the ICU Unit at the hospital's infirmary and cared for by members of the Daughters of Charity, all RNs. My family was not allowed to stay on the premises so they returned to Baton Rouge and stayed at a local motel. They returned the next morning for a brief tour of the huge hospital. Their departure soon after was one of the saddest moments of my 20-year life. We all cried while waving good bye. My introduction to HD had begun as I became patient #2855 at the national leprosy hospital in Carville, Louisiana.

The campus was 350 acres encircled with 10-foot-high cyclone fences, and a swamp with alligators. Housed there were 450 patients from many parts of the United States and other countries. Hundreds of personnel lived on one side of the facility and patients on the other, with an unwritten rule that patients were not to cross an imaginary line.

The hospital was operated by the State of Louisiana from 1894 until 1921 and then by the United States Public Health Service. In 1982, 13 outpatient clinics were opened in 10 states, including three in Texas. In 1999, the USPHS stopped admitting patients and returned title to the property to the State of Louisiana. The facility is now an armory for the Louisiana National Guard. The facility also houses the National HD Museum where my small travel bag resides.

Many treatment options for my ENL were tried by the doctors, but the ENL stubbornly returned. As days became weeks and weeks became months, the MDs finally recommended the use of thalidomide to combat chronic fevers. Carville became my home for 2,476 days. The stay left me with many physical and emotional scars. None of the scars were as great as the ones suffered by those who spent decades as patients and are buried on the grounds under large pecan trees. The cemetery is perfectly manicured and looks like a mini-National Arlington Cemetery.

For my first year at Carville, I shifted beds from an assigned tiny bedroom in one of the eighteen "patient quarters" or dormitories (House 23) with communal baths, and the Infirmary. I would navigate the long perambulators (elevated, two-story walkways) which "integrated the residential, hospital, research buildings, cafeterias, utility buildings and Sisters Quarters." The two-mile-long walkway was enclosed with large screened windows keeping every hungry mosquito at bay. The facility was designed to be self-sustaining, and isolated in location, in order to prevent "unauthorized outings" by the patients. This design, long implemented before the American Disabilities Act (ADA), was able to link the huge facility physically and aesthetically. Initially, I would travel on a hand propelled wheelchair, as did many other patients, to appointments and meals. As I regained my strength, I traveled the walkways by bicycle, the preferred means of transportation for patients and staff.

I was educated about thalidomide by being informed that the "right dosage" had to be determined by trial and error. The doctors eventually settled on 100 mg QID (four times a day). By then I had been granted special per-

mission from LSU, the hospital administrators, and the Texas Rehabilitation Commission to commence my college studies at LSU. At the time, my diagnosis was deemed to be a “permanent disability.”

Taking the equivalent of four strong sedatives daily took an immediate toll on my sleep patterns. In order to counter such, I was prescribed amphetamines. I needed to stay awake, especially in order to address my studies and drive safely to LSU. With special permission from the university and hospital administrators, I was allowed to commute to LSU. The security guards at the gate would document my departures and returns, with no allowances for being away overnight. I completed a Bachelor’s degree and Masters in Social Work while still on thalidomide and other drugs. The support from my family, hospital staff, and other patients greatly contributed to my success at school.



Jose and his parents celebrating at LSU after his Bachelor’s Degree ceremony. By this time his complexion was getting darker from medication.

Another experimental drug administered was clofazimine, which turned my complexion black. Being “black” in the 1960’s in Louisiana is a story left for a later article. These drugs, along with Dapsone, Rifampin and prednisone, became referred to as MDT (multiple drug therapy). All contributed to my eventual freedom from the HD bacillus, but not from the centuries old images of “the Biblical disease.”

My ENLs eventually subsided and I was able to cease taking thalidomide. Although the blue pill was banned in the U.S while I was on the “experimental drug,” it slowly regained its status as a miracle drug worldwide. Thalidomide has helped many of my brothers and sisters throughout the world. My “sisters” are prescribed such only under intense scrutiny and severe restrictions as thalidomide can still cause birth defects.

Thalidomide is now used for many ailments beside HD. Thalidomide is commonly used to combat rheumatoid arthritis, lupus, inflammatory bowel syndrome, TB, chronic nausea, profuse sweating, itching, seizures, certain cancers, and many other conditions.

I lost many days of awake time while at Carville, but I am very proud to have been part of this experiment. Thalidomide has gone from a miracle drug, to a monster drug, to a miracle drug again. I was extremely lucky to have been diagnosed, and arrived at Carville, at a time when so many experimental drugs were being used to combat HD. I have also felt much sadness as thousands who arrived at Carville before I did were unable to benefit from these drugs, and the opportunities to further their education. As I enter my seventh decade being alive, I am grateful for the love shared by my parents during this journey. This journey meant years of separation from my family, and Magdalena, waiting for my discharge. My twelve siblings were constantly supportive as they mailed me get well cards, spoke via phone (Carville had only two phone booths), and my parents tried to visit annually.

Magdalena and I married on a December 24th, symbolically resurrecting my life. Our adult children and their respective spouses have become great advocates for combating prejudice and injustices experienced by those with misunderstood and feared illnesses, and enlightening others about dignity and respect. My work as a licensed transplant social worker in Houston allows me to navigate the halls of advocacy as my personal journey with thalidomide can impact those with HD, and other misunderstood illnesses.

The Hidden Faces of Discrimination

by Jose Ramirez, Jr.

My son JR Ramirez has written an article about a community in Ukraine. These were persons with Hansen's disease (HD) who were not recognized as individuals in need of medical care. Such was the case because the country did not report HD to WHO (World Health Organization). This example is one of many throughout the world where countries might intentionally, or unintentionally, cease to recognize the existence of persons with HD. This practice has contributed to the existence of discriminatory laws, health policies, and general practices in the populace.

In an effort to eliminate discrimination, hundreds of individuals who have experienced HD, or been impacted by it, have assisted the UN Special Rapporteur in identifying laws and practices which discriminate and disrespect this unique population. For me, the most glaring, and emotionally damaging laws, are the ones allowing for divorce on the grounds of HD. The stigma felt by persons who fall under this category swells tenfold as their quality of life is changed forever. This is especially so for women who have already faced lives of subservience. However, men are also impacted by these divorce laws as evidenced by men in Ethiopia who have fought such laws all the way to their country's Supreme Court, and lost.

Laws which are enacted as a form of discrimination occur oftentimes because of the dearth of knowledge about the disease. Biblical images, painful stereotypes and traditional practices add fuel to a fire stoked by poorly informed legislators. Furthermore, similar to institutional racism, institutionalized discrimination can become imbedded in the minds of society's youth. The only way to eliminate these laws and practices is to attack the systemic forces and create change. Persons with HD have experienced labeling, rejection, and fear but have risen above the stigma. They have become social scientists, and experts, in the world of HD. Persons who have experienced HD are the ones who need to be partners in the culture of change. Persons who have experienced HD are the ones who need to be sitting on boards and legislative bodies providing guidance to colleagues who can collaborate on change. The year 2022 is not too late for all opposed to discrimination to bond into one. Let us know your thoughts by writing To The Editor Jose Ramirez, Jr. joseramirezjr@hotmail.com

Time for a Victory Garden? by Tom Adams, Directeur Carville Star

As I write this, the mild temperatures of spring are upon us, signaling time for commercial and home gardeners to till the soil and prepare for planting. Given "supply chain" issues and inflated store prices for fruits and vegetables, it might be time for us to consider a Victory Garden.



One of the many posters promoting Victory Gardens during WWII

Victory Gardens appeared during both World Wars, about 20 million during World War II. Throughout the war food was in short supply because much of the processed and canned foods was reserved for shipping overseas to our military and our Allies. Also, gasoline and tire rationing limited the transportation of food, and food transports were never prioritized above soldiers and war supplies. The government encouraged citizens to provide their own fruits and vegetables from their Victory Gardens, so that commercially canned fruits and vegetables could be reserved for the troops. Fueled by patriotic zeal, citizens planted gardens in every outdoor nook and cranny to include rooftops of city buildings. Friends and neighbors often came together, each growing different crops for sharing among themselves.

Patients at Carville (United States Marine Hospital Number 66, The National Leprosarium of the United States) were noted for their patriotism during World War II. Even with limited personal finances, the patients prided themselves in the purchase of War Bonds and creating Victory Gardens. In June 1942 The STAR (the patients' newspaper) documents these gardens at Carville.

"Carville is taking the idea of Victory Gardens very seriously. The front, side and rear of the houses are now in the greenest of gardens and the side of the golf course not actually needed for the game is lined with them. Every imaginable vegetable is planted and thriving."

In March 1943 The STAR again addresses Victory Gardens and their importance during a time of food rationing.

"We have always had quite a few vegetable gardens in Carville, but this year the entire male population, reinforced by some farmerettes, seems to be employed as one body to dig, weed, fertilize, and plant everything good to eat. Some of the gardens are no larger than the one in your back yard and some are as large as that one on the vacant lot next to your house. Without ration books it is Victory Gardens or no home cooked suppers. "

Despite the challenges of their life as patients with Hansen's disease, patients at Carville proved themselves patriotic citizens capable of doing their part to insure victory over oppression.

Twenty-first International Leprosy Congress to be Held in India
by David Scollard, MD

The 21st International Leprosy Congress will be held at the HITEX Exhibition and Convention Centre in Hyderabad, India, Nov. 8-11, 2022. The theme of the Congress is: 'Better knowledge - Early diagnosis - Improved care'.

This unique meeting (now held every three years) gives leprologists, basic- and social-scientists, national program managers, NGOs, and leprosy workers from around the world a prestigious platform within which to present their latest research and share their best clinical experiences. The Congress will highlight many new developments in leprosy research since the last Congress in Manila in 2019. ILC 2022 also offers young researchers a range of rewards, as well as an unparalleled level of international exposure. Many persons who have experienced HD are expected to attend and make presentations, and the Sasakawa Foundation is planning a special pre-Congress meeting to discuss their concerns.

Due to Covid concerns, this will be a hybrid meeting with both physical and web-based sessions. This will allow more than 110 hours of scientific sessions, and the ability to accommodate over 2,500 physical delegates and unlimited virtual participation. Different fees apply for in-person vs virtual attendees.

International Leprosy Congresses are convened under the auspices of the International Leprosy Association. The 21st ILC is being organized by the Indian Association of Leprologists (IAL) and the Indian Association of Venerology and Leprology (IADV) with the support of Central Leprosy Division (CLD) NLEP, Ministry of Health & Family Welfare, Govt of India. The organizing committee is chaired by Dr. P Narasimha Rao, Professor of Dermatology at Bhaskar Medical College in Hyderabad and Chairman of the IAL.

For additional information, and to register for the Congress, please visit the website at www.ilc-india2022.com

The Star by the Numbers:

Like the "Little Engine that Could" this journal has chugged along for 81 years radiating the truth about Hansen's Disease.

Currently it delivers a 16 page issue twice a year to Six continents, Twenty nine countries, Twenty two states, Fourteen clinics, For a total of almost 1600 copies.

This feat is accomplished through the combined volunteer efforts of One managing editor, Six board members and 18,000 members of the Forty and Eight. And the biggest bargain of all-- this gem still costs only \$2.00 per year in the United States and \$5.00 per year internationally.

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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 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 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 dapsone, 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