

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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The American Legion formed a post at the hospital in the early 1930s. Patient veterans took an active part in lobbying congress for hospital improvements. The 40 & 8, an independent fraternal organization of U.S. veterans, took up the cause of the patient newspaper “The Star”.

A rich tradition: Carville, the American Legion and the 40&8 page 3

CONTENTS

January 2019-June 2019 Vol. 64-25

A Rich Tradition: Carville, the American Legion and the 40&8 By Tom Adams and Claire Manes.....	3
William Kikuchi 1932-2019 By Anwei Skinsnes Law.....	5
Encouragement Exemplified by the Daughters of Charity at Carville By Tom Adams	7
Persons Affected vs Persons Who Have Experienced (Hansen's disease) By José Ramirez, Jr.....	9
Zero Leprosy: An Ambitious Mission By Courtenay Dusenbury.....	10
Learning To Educate By Erika B. Ramirez	12
Remembering Morris Koll, Veteran, Carville Patient and Grandfather By Matthew Koll.....	13
Hansen's Disease Clinics.....	15

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Founder - Editor, 1941 - 1967

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

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A Rich Tradition: Carville, the American Legion and the 40&8

By Tom Adams and Claire Manes

Almost 100 years ago on September 16, 1919, the United States Congress chartered the American Legion as “a patriotic veteran’s organization.... focusing on service to veterans, service members, and communities.” That simple statement from the Legion’s website only begins to illuminate the work of the organization during the past century, but it does presage an important event for the Carville, Louisiana, hospital community for much of the last hundred years.



On a Sunday in June 1931, twelve years after its formation, the Legion came to Carville. Stanley Stein in his memoir *Alone No Longer* recalls the occasion when, “the barbed wire which cut us off from the world began to sag.” A patients’ group of 20+ veterans of the Spanish American War and the Great War met with Sam Jones, Louisiana State Commander of the American Legion, and other Louisiana Legionnaires to express their needs and air their grievances as veterans and forgotten human beings. It was perhaps the first time that a group of Carville residents, including Edmond Landry (a WWI veteran, aka Gabe Michael and the grandfather of Claire Manes), had bonded as a force to advocate on behalf of themselves and their fellow patients. On that day the residents found a new friend and ally in the American Legion and a new lease on life.

It is intriguing that 20+ veterans would vault patient concerns at Carville to national prominence through a relationship with a newly-formed American Legion. It was fortuitous that someone as politically influential as Sam Jones, Department (Louisiana State) Commander of the Legion and later Governor of Louisiana, could lead the charge on behalf of Carville patients. At their first meeting with Commander Jones, patients expressed concerns over lack of recreational activities and an inadequate hospital; both needs were promptly addressed by the Commander.

An article Commander Jones wrote for the Legion's national magazine represented the first time someone from the "outside" advocated improvements to living conditions at Carville. The Legion wasted little time in bolstering its relationship with Carville patients and achieving connections to the world beyond the fence. Within weeks of the June meeting the Legion had invited baseball teams from Baton Rouge and environs to play on the Carville diamond and had sponsored bands to perform for hospital dances.

The Legion acted politically on a national scale as well, as they pursued legislation to affect changes in Carville. In less than one year from the initial meetings Legion members had successfully lobbied in Washington for a new hospital facility in Carville that was completed in 1935. They also teamed with Carville's Patient Federation to gain approval for a five million dollar project to replace wooden buildings and housing with modern, fireproof structures. These buildings opened in 1941 and featured a massive recreational facility replete with a ballroom, post office, library, canteen, and lounges.



Patient leaving infirmary in station wagon donated by the American Legion Auxiliary, 1940's

They also teamed with Carville's Patient Federation to gain approval for a five million dollar project to replace wooden buildings and housing with modern, fireproof structures. These buildings opened in 1941 and featured a massive recreational facility replete with a ballroom, post office, library, canteen, and lounges.

In other instances the Legion acted to achieve seemingly smaller but no less important improvements to patient life. It gained state support to install the first telephone for patient use in Carville. According to Stanley Stein the Legion succeeded in lifting the ban that had prohibited the patients from returning empty Coca Cola bottles to the distributor for refunds. Prior to the Legion’s actions, the local Coca Cola distributor would sell the product to Carville but, fearful of repercussions from other customers, he would not accept empty bottles for cash.

While there were incremental changes from 1931 onward, patient reform efforts accelerated with the formation of the National Advisory Committee, formed by Legionnaires and physicians appointed by the surgeon general. The first meeting occurred in 1946 opening new and significant doors to patients. In that first year of its formation the committee and patients pressed for and finally achieved voting rights. At about the same time, with assistance from the Patient Federation and The Star, the gates of Carville were opened to visitors to freely interact with patients. In December of '46, patients learned that the advisory committee had acted upon many patient concerns including hiring a professional writer to assist The Star's editor and acquiring more liberal leave for patients.

The American Legion Auxiliary was equally supportive of patients' needs. By 1949 the Auxiliary had contributed four station wagons to transport Carville patients. They also were helpful in many of the patients' recreational activities including baking cakes for support of golf tournaments. One particularly poignant and practical gesture was undertaken by the American Legion Auxiliary of Bogalusa Louisiana, The group hired a seamstress to sew for incapacitated women patients. Though much of the public feared close personal contact with patients this group and the seamstress they hired let compassion trump fear.

Besides the Legion and its Auxiliary, Stanley Stein recognized the 40&8 as the third veterans' organization to appear at Carville. He notes, "I hesitate to think what the hospital would be like today if veterans had not been committed here, for it was through the vets that the national organizations became interested in Carville as a whole." The 40&8 began as an invitation only honor society of veteran members of the American Legion. It took its name from the French box cars used in World War I to transport American soldiers to the frontlines in France. The cars could hold forty men and eight mules, hence the name La Société des Quarante Hommes et Huit Chevaux or the 40&8. The name is apt, for the members of the 40&8 continue to work with persistence and vigor on behalf of both Carville and their other national causes including efforts for the welfare of children.

The first documented contribution of the Forty and Eight at Carville occurred in 1943, when a voyageur from Arkansas contacted the 40&8's Grand du Louisiana regarding the need for a printing press for The Star. In December 1943 the Grand presented a press and all its accessories as a Christmas present to Stanley Stein and The Star.

In 1959 the 40&8 severed its ties with the American Legion becoming a separate and independent organization. While the Legion influence and activity at Carville waned with the passing of the years and diminished demand for advocacy of patient grievances, 40&8's support to Carville remained steadfast. The Carville Star Program is currently one of the 40&8's seven major programs. As such it funds publication and distribution of The Star, keeping alive the legacy of "radiating the truth about Hansen's disease." The Carville Star Program funds projects for the Carville Historic District, including the cemetery and the museum. Most recently the group installed interpretive signage throughout the District for touring visitors. The National Hansen's Disease Museum at Carville, the beneficiary of 40&8 support, houses displays to tell the story of 40&8's involvement at Carville.

The 40&8 is a proud organization with Carville tightly bound into its history and tradition. No other veterans' organization has as a declared mission to disseminate information to promote understanding of a disease. Tom concludes, "my comments in the 40&8's magazine sum up my feelings about the relationship and the strong bonds that have been formed."



Our La Société is an organization filled with traditions incorporated into our rituals and our programs like Carville Star. *In the musical Fiddler on the Roof, Tevye addresses the importance of tradition when he says "Because of our traditions, we have kept our balance for many, many years...we have traditions for everything...You may ask, how did this tradition start? I'll tell you. I don't know. But it's a tradition. And because of our traditions, every one of us knows who he is, and what God expects him to do. Traditions, traditions. Without our traditions, our lives would be as shaky as... as... as a fiddler on the roof!" And so it is with La Société with our traditions insuring our identity - who we are and what we stand for."*

William Kikuchi 1932-2019

By Anwei Skinsnes Law

“Because of what I have endured, I try to instill in my family that discrimination for any reason is wrong for it breeds hate. It can and it will consume you . . .

I admire people for who they are, for what they do”

-- William Kikuchi

William Mitsuru Kikuchi, Editor of The Star from 2004-2006, passed away peacefully on Monday, February 18, 2019 at the age of 86. He was an instrumental force behind The STAR long before he became the Editor. He was married to his beloved wife Margaret Garrett Kikuchi for 50 years prior to her death in 2009 and they had four children, seven grandchildren and two great-grandchildren. The son of John Y. Kikuchi and Isako Kataoka Kikuchi, he had five brothers, two of whom married Margaret's sisters. Certainly he felt that his greatest accomplishment and his greatest gift was his family.

Will also played an instrumental part in IDEA, the International Association for Integration, Dignity & Economic Advancement for 20 years. For many years he designed the IDEA newsletter and ensured that it was mailed out to people around the country and around the world. He also served on the Board of Directors of IDEA. In 2002, he and Margaret were participants in the First International Conference for Women Affected by Leprosy/Hansen's disease, held in association with Women's Rights National Historical Park in Seneca Falls, New York.

In 2008, an interview with him was included in *Illuminating Ourselves*, published by the IDEA Center for the Voices of Humanity. His kindness to others, despite years of facing discrimination, will be remembered by all who knew him and are printed here in tribute to his wisdom and years of friendship:

“My parents both came from Japan. When my mother got the disease, I remember seeing her when she was in isolation in the hospital in California before being transported to Carville. I remember seeing her at the window, waving goodbye to her. That was in 1935, and I was three years old. We were separated from the whole world, I guess, because we weren't supposed to associate with anyone. I didn't reach out for friends, because there were none. I never complained since no one would listen and all I would receive in return would be more hate. I learned to accept whatever happens, be it good or hurtful. The only friend I recall was someone with tuberculosis. He was treated as we were, so in our shame we became friends. Things were looked at much differently in those early years. We kept mostly to ourselves. We were outcasts.

“On the day Pearl Harbor was attacked, we were coming home from church and I remember being shot at. They were laughing and cursing at us as we ducked into alleys trying to get home. I'll always remember that. Soon after, they came and dismantled our radio. That didn't matter since it wasn't working anyway. We were sent to a Relocation Center and then on to the concentration camps. I wound up living in four of these camps. We could only take a minimum amount of clothing; no weapon or sharp objects were allowed. What you didn't destroy was confiscated by the government. We didn't have much so it didn't matter. My mother had been misdiagnosed for so many years and treated for other diseases. It had drained my dad physically and financially, so before my mother left they were on the watch for a double suicide.

“While in camp, my father and older brothers would leave the camp for employment for months wherever work was available. Another brother of mine, who was two years older, but also too young to go to work outside the camp, stayed behind and we took care of ourselves. I know I didn't eat much because I didn't have much to eat. I only ate rice. I never

drank milk. The only thing I ever drank was tea. I worked most of the time. I remember when I was nine years old in the camp, I'd get up at 3 or 4 o'clock in the morning to look for jobs. I always wanted to drive a tractor but I couldn't reach the pedals. So my job was mostly hauling things in wheelbarrows and shoveling horse dung. That was the only job I could get. We had no supervision. We became very independent. We never knew anything different. I had nothing to compare it with.

"I was well conditioned for accepting Carville because I lived my life behind fences, surviving the ordeal of living. Being discriminated against became a way of life with me. So it wasn't a challenge. I accepted the life I was given and tried to make the best of it. When I entered Carville in 1946, my doctor said I would die in five years. I was discharged six years later very much alive. But, I left with their instructions in my mind. Do not shake hands with anyone, avoid all bodily contact and do not get married. Most important do not have any children for they would suffer the same 'curse'. So I left with their 'farewell message' of 'enjoy' your life while you can.

"Most people tell me that I must have suffered a great deal. Through all this I learned what it is to be hated and to be denied your rights. It is now 58 years later. I have been married for 45 years and have four children and seven grandchildren. Because of what I have endured, I try to instill in my family that discrimination for any reason is wrong for it breeds hate. It can and it will consume you. It's a funny thing, when you're ill with a disease like we had that used to require isolation, all the people they lose their identity, more or less. They become one . . . We were all brothers under the skin. I never really looked at a person and felt that they were different.

"I admire people for who they are, for what they do, for themselves, what they do things for . . . I have found that people who don't have an education have many things to say that, if you listen, will really touch your heart."

One summer Willie and Margaret took care of the IDEA Center for the Voices of Humanity in Seneca Falls, NY. He put a bell on the door that is still there and rings every time someone comes in. Interestingly enough, the IDEA Center now shares space with The Seneca Falls It's a Wonderful Life Museum. Both have the same message – the message that Willie promoted – about the value and importance of each individual. In 2018, more than 11,000 visitors came through the doors and each of them heard Willie's bell ring as they entered and as they left. Upon hearing the bell, many said: "Every time a bell rings an angel gets its wings." Without any of us knowing it, Willie gave us our It's a Wonderful Life bell that will continue to ring long into the future.

Editor's Note: Willie, two of his brothers and I often compared how we were maliciously labeled as children due to our respective heritages. We became even closer as I learned how the Kikuchi brothers were stars on the Carville Indians softball team winning the River League Softball Championship in the early 1950's. My love of the sport and my knowledge of the rules having been an umpire prior to my admission to Carville solidified our friendship. Neither of us could have imagined another similar journey on being part of the eight Editors of The STAR. I miss you dear friend.



Will with his family: (Left to right) Nikki, Margaret, Cliff and Anna.
(Cliff Kikuchi facebook post)

Encouragement Exemplified by the Daughters of Charity at Carville

By Tom Adams, National Directeur Carville STAR

*Encouragement like flowers can brighten a way,
Turn storms into rain paint colors from grey.
Find good in the bad bring laughter from pain,
Lift up a spirit even loosen a chain.*

-Jim Ness

I am privileged to coach a basketball team of persons with disabilities. During pre-game warm-up before a recent game one of my players was unable to shoot the ball high enough to reach the rim of the goal. However at his first opportunity to shoot in the game, I noted he first glanced to the crowd where his caregiver was cheering him on, then took a shot that easily cleared the rim and went through the net for two points. I believe that encouragement from his caregiver was responsible for propelling the ball beyond a height unreachable during warm-up.

Encouragement is a gift that we all have the ability to give. And so it was with The Daughters of Charity, a **Society of Apostolic Life chartered to serve the sick and the poor**, as they nurtured Carville patients through encouragement. In 1896, about 2 years after the opening of what was then the Louisiana Leper Home, four sisters of The Daughters of Charity answered the call to serve as nurses for patients. One of the sisters, Sister Beatrice wrote that upon their arrival “We went to each one (patient) separately and tried to make them feel we were coming to be one with them, to care for them, to make them happy ... to show them the goodness of God their Father providing for them in their suffering and lonely condition.”



The first four Daughters of Charity of St. Vincent de Paul arrived at Carville on April 17, 1896. With Father Michael Colton, then chaplain, and Sister Beatrice Hart and Sisters from left to right, Mary Thomas Stokum, Annie Costello and Cyril Coupe

From the moment they set foot at Carville after an 18 hour trip up the Mississippi River from New Orleans, the sisters provided encouragement to patients. The sisters found a majority of the patients to be Catholics who believed they had been abandoned spiritually. Sister Beatrice wrote that the patients watched the



Young patients, staff, and sisters at Carville- c. 1920

boat..."until we finally stepped out. We told them that we had come to stay, wishing to do all that we could to comfort their lonely, suffering condition. It was touching to see the happiness of these poor people when they caught sight of the Sisters. They almost wept with joy. ‘Have you really, really come to stay with us?’ they kept repeating." Years later, in her poem *To Carville - The Hospital*, Ymelda Beauchamp in a nostalgic look at the impact of the sisters (The Angels of Carville) penned "Remember all the angels dressed in their white gowns That understood our fears They held us in their bosom And dried up all our tears?"

The sisters were the first social workers at Carville, encouraging the patients to find ways to pass the time so they would not dwell on their condition. Despite successes as social workers, as Carville grew in patients and complexity it did not take long to recognize that social work alone could not fulfill comprehensive patient healthcare needs. In 1916 Sister Catherine Sullivan, a graduate nurse, arrived at Carville. She was followed by a succession of sisters with certifications and credentials in nursing and other healthcare professions, able to fulfill staffing requirements at Carville.



Sisters and staff member in Carville pharmacy

In addition to their service as nurses, The Daughters of Charity served as administrators, pharmacists, laboratory technicians, medical record custodians, x-ray technicians and more - credentialed and certified in most cases. For over a century, a total of 116 sisters staffed the Carville hospital.

Sister Catherine Sullivan was to become perhaps the most influential sister in Carville's history. Early in her distinguished career at Carville, Sister Catherine was concerned with injustices in the treatment of Hansen's disease patients. Her stance was often made public with statements like "Patients with Hansen's disease are still crucified on the cross of public opinion, held there by the three nails of prejudice, fear and ignorance, and the final spear thrust given by the knowledge of their helplessness." Her credibility as a graduate nurse drew the attention of the public when she wrote "I would take more precautions nursing a case of influenza than of Hansen's."

Sister Catherine convinced patients of the power of the written word. None other than Stanley Stein and Betty Martin were beneficiaries of her encouragement, leading to publication of Stein's *Along No Longer* and Martin's *Miracle at Carville* and *No One Must Ever Know*. Sister Catherine's encouraging yet challenging words to both authors and other patients was "If I have a fault to find with you it is that you fail to grasp the great role that is yours. Is it a small thing that you have an opportunity to change world opinion ...? In your hands rests the fate . . . of every sufferer from Hansen's Disease throughout the world You have a date with destiny." In 1941, with such encouragement, Stein and the staff of *The Star* began their successful quest to "radiate the truth about Hansen's disease." Sister Catherine's influence continued into the mid-1940's when she led a national effort to recognize outpatient treatment of Hansen's disease (HD).

Merriam-Webster defines encouragement as "to inspire with courage, spirit, or hope." The history of The Sisters of Charity at Carville embodies that definition. Even today, each of us must remember the admonition of Sister Catherine "You have an opportunity to change world opinion (about HD)." May these words forever encourage us to take action in response to her challenge.

Persons Affected vs Persons Who Have Experienced (Hansen's disease)

By José Ramirez, Jr.

One month before I was admitted as patient # 2855 to the U.S.P.H.S. Hospital in Carville Louisiana in 1968, the founder and first editor of The Star passed away. On the first day of my admission I was provided with a copy of the Star's issue highlighting Stanley Stein's accomplishments while at Carville, including his goal of "radiating the light of truth about Hansen's disease" (HD). Initially I did not think much of this unique journal but as the years passed, I realized that the use of the term leprosy oftentimes resulted in the general population using the five letter "l" word used in the Bible, the only disease mentioned in this important document. Mr. Stein, as millions before him and millions after him, experienced the pain and trauma of being referred to by the "l" word and thus tattooed with stigma.

Stigma has a history of being associated with a "mark" as in the mark or pejorative term that arises when "punished by God." Stigma has the effect of denying persons their basic human rights and privileges usually caused by practices passed on through many generations, and usually resulting in involuntary placement in institutions for decades. These practices in the past have become policies or legislation still alive in 2019. The consequence is that persons who have felt this stigma become fearful of rejection, impairing their quality of life.

The V International Congress on Leprosy in 1948 in Havana, Cuba highlighted the accomplishments of two men from Carville. One was Dr. Guy Faget who was in the forefront of the discovery of the sulfone drugs (the "miracle" drug). The second was not present but talked about as "one who has started a unique campaign to educate the public about Hansen's disease." The difference between these two "highlights" was that the former sprouted the growth of research which continues today and the latter appeared to have been dismissed as a novelty as is the case today. Stein, like thousands others of his time were strong advocates segregated from society. In 2019 it is challenging to be an advocate of change as the audience is the larger community and not just the administrators of an institution.

Historically persons who have been attacked by the tiny bacillus have also experienced attacks by society in general. The attacks have been both physical and emotional. Emotional attacks result from the pain of being labeled the "l" word. Other words have evolved in different languages but one which occasionally will surface is "patient," as if those with the bacilli now or in the past will always be seen not simply as persons but as persons with a condition. Another term has been "persons affected by leprosy," an effort to use person first language but which also gave birth to the acronym PAL. At the XV International Congress in Beijing, China in 1998 Dr. Gopal from India and I presented to the members that PAL is another label and not acceptable to our brothers and sisters. A recent article in BMC MEDICINE further labels us as "from a low socio economic status, a low level of education, little awareness of human rights and vulnerable to discrimination."

What the world needs to know is that in 2019 there are millions of our brothers and sister who have been cured of Hansen's disease; millions who have ended up with multiple disabilities of the body and soul as a result of limited physical and behavioral care; hundreds of thousands who live with impaired quality of life; and hundreds of thousands labeled as "new" cases. The end result is that we have not simply been "affected" but have unique LIFE EXPERIENCES which can help in lessening stigma and enhancing quality of life via as advocates or peer consultants when the right resources and training are made available to mobilize capacity building. Therefore, the use of persons who have experienced HD should be used to address us, and even better would be to simply call us by our names.

Zero Leprosy: An Ambitious Mission

By Courtenay Dusenbury, Secretariat Director, The Global Partnership for Zero Leprosy

Since coming to the Global Partnership for Zero Leprosy just over a year ago I have been privileged to have benefited from the wisdom from numerous people—from disparate countries, social and economic backgrounds and professions—who have experienced Hansen’s disease (leprosy).

While the circumstances, duration and impact of the disease have been different for each person, the universal message is clear: the impact of leprosy on individuals and their families cannot easily be understood by those who haven’t experienced it. This experience, and this understanding, are crucial to ending leprosy.

Ending leprosy isn’t the job of just one group. Everyone has an important role and a place at the table. To be successful, we will need scientific innovation, national program excellence, a strong drug donation program, social justice, economic empowerment and an understanding of the impact of stigma and other barriers to treatment. Ending leprosy requires the talents of everyone: people who have experienced leprosy, scientists, program directors, policy and political leaders.

Each of us has something to learn from listening to each other. We can be stronger when we are willing to be open to other viewpoints, support each other and work together toward a common goal. This vision of solidarity is a fundamental belief and organizing principal of the Global Partnership for Zero Leprosy (GPZL), a coalition of dedicated people committed to ending Hansen’s disease/leprosy formed in 2018.

The vision of the partnership is ambitious: No disease, no disability, no discrimination, and no stigma. Our partnership unites the unique expertise and experiences of 450 organizations and individuals. Our leadership team includes representatives from IDEA, ILEP, the national leprosy programs of India, Brazil and Ghana, the International Leprosy Association (ILA), the U.N. Special Rapporteur, WHO’s Global Leprosy Programme, and Novartis.

The GPZL’s Action Framework defines Zero Leprosy and lays out a plan to get there. Our Operational Excellence working group of 180 members is developing a Zero Leprosy Country Model. This model uses country-led mapping, evaluation and visioning to help nations develop their own roadmaps. These roadmaps lay out a plan and the methods for working towards ending leprosy in individual countries and will be supported by funding and technical assistance, including an online toolkit and help desk. Organizations of persons affected by leprosy will be integral to these efforts on the national and community levels.

We also want to make sure there’s funding for new leprosy research and programs, including the areas of stigma





Staff and members of the Global Partnership meeting in Greenville, South Carolina in April, 2019.

and discrimination. This year, 144 GPZL members worked together to develop an aligned research agenda outlining the priority research needed. We are committed to funding that research and are actively seeking investment for it.

The GPZL and our partner organizations are also engaged in advocacy on the global and national levels. Over 150 laws still discriminate against persons affected by leprosy in 29 countries. A core value for GPZL is that discrimination on the grounds of leprosy is unacceptable and violates enshrined international human rights.

Before coming to the GPZL I thought it unique and interesting that persons affected by the disease were so engaged in efforts to combat it. Now I wonder why this is not the norm for all diseases. The impact and experience of persons affected by leprosy, and the way they are involved in the advocacy and political processes, is an example that should be taken on by all anti-disease coalitions. I have come to appreciate that the leprosy community is really leading the way. Others should take on its approach, to ensure more comprehensive, productive and meaningful partnerships.

We invite you to join us and give us feedback through our website www.zeroleprosy.org and on Twitter and Facebook @ZeroLeprosy.

1. Source: <https://www.ilepfederation.org/what-we-do/zero-discrimination/table-of-discriminatory-laws/>

Learning To Educate

By Erika B. Ramirez

“What’s wrong with his legs?” a friend asked me when my Dad picked me up from elementary school. I knew that Hansen’s disease scarred his legs, but I never thought the scars signified that something was “wrong” with him.

By then, my brother and I were familiar with my Dad’s experiences. We knew about his time as a patient in Carville, Louisiana. I remember visiting the Carville cemetery late at night during Christmas break. Since my brother and I fancied ourselves horror movie fans, I am sure my Dad chuckled to himself watching our terrified reaction. Despite moments of levity, we understood the significance: unlike my Dad, many others never left Carville’s grounds.

We understood Hansen’s as a medical condition. My Dad also taught us about the societal stigma associated with the disease. The “L-word.” Nothing could fully prepare me, however, for the emotional response I experienced once confronted with this unfortunate reality.

I remember the first occasion. I was watching *The Simpsons*, a daily staple in our household during the mid-nineties. My reaction was immediate – I felt anger. My face burned. My beloved *Simpsons*? How could they make light of a medical condition that affected so many – including my Dad and those at Carville? I logged onto America Online and found a website using the offensive clip. I emailed the site manager and asked that he take it down, explaining the reasons. The site manager didn’t care.

As time went on, my taste in television changed. I remember watching an episode of *Sex in the City* in college. Suddenly, a main character blurted out that she felt “like a leper” further elaborating that she felt like “an outcast.” A familiar feeling rushed through my body. About ten years had passed since *The Simpsons* incident, and, yet again, one of the most famous television programs was using the L-word? How could they not know? I felt angry and disappointed that my Dad and others still had to face ignorant statements in the media. I felt powerless and ashamed. Had I not done enough?

Years later, I sat in a classroom as a first-year law student. My favorite professor lectured on defamation. He said, “Defamation occurs when someone has lessened your character. For example, if someone calls you a prostitute...or a leper.” My face burned. My hand shot up in the air. My words were loud and clear as I took the opportunity to explain that the L-word is demeaning and inappropriate. My professor, red-faced, immediately apologized. He apologized again in private, and classmates approached me to learn more about the L-word’s hurtful impact.

It was a small victory. People could learn and change – and, in my small way, I could help make that change. I now find myself being increasingly proactive about educating those around me whenever the opportunity presents itself. I hope that society’s progression on this issue continues and that the L-word soon becomes a relic of the past.

Remembering Morris Koll, Veteran, Carville Patient and Grandfather

By Matthew Koll

Private Morris Benjamin Koll was born in 1884. He died in 1938, while a patient at Carville. He was interred in Arlington National Cemetery on December 27, 2016. Surely the last Spanish-American War veteran to find his way there. His was a long and difficult journey.

Morris Koll was my grandfather. Morris was 16 when he joined the U.S. Army. He served in the Philippines and fought in the Battle of Bayan. He returned home to New Haven, Connecticut in 1904, infected with the Hansen's Disease bacillus.

Due to the disease's long incubation period, it was 1923 before he was diagnosed with Hansen's Disease. The night of his diagnosis he fled to New York City, New York being one of the only states not requiring that all leprosy patients be sent to Carville. Morris had to leave his wife Dora and three children behind for a couple of years, as Dora looked after Morris' butcher/grocery business and the children.

Resettled in New York, Morris spent the next decade trying to provide for the family's future, even as his symptoms grew worse – his butcher's hands going numb and clawed, his eyesight dwindling. My father recalled coming home from school each day, after Morris had gone blind, sitting with him and reading him the newspaper.

One morning in 1935 my father went off to school, and when he came home Morris was gone. The U.S. Public Health Service had taken him and was transporting him to Carville. My father never saw him again.

Dora, doing what the stigma of leprosy caused many people to do, swore my father and his siblings to secrecy. When Morris died three years later his fellow veterans in the Carville American Legion post arranged for his funeral. My father did not learn where his father was buried for sixty years.

As far as I knew, growing up, my grandfather had died at some unknown military hospital of some unnamed tropical disease he'd contracted in the Philippines. A little bit of truth in there I suppose. I never did buy the story, but my parents clammed up on the subject. It was simply not spoken about.

Flash forward to 1998, when out of the blue my father telephones to confess a secret. His father's disease had been leprosy. And my 79-year-old father couldn't hold that in any more.

It took my sister little time to discover that Morris had died at Carville. And thanks to the very helpful people there, especially the Public Health Service's Lila Davis, we learned that Morris was buried in a small Jewish cemetery in Baton Rouge. We took a family trip, toured Carville, then drove to Baton Rouge and found the cemetery. In a far corner up against a fence was Morris' grave. My father wept and placed pebbles on his father's headstone.

Over the next 17 years my family returned to the cemetery several times. On each visit the area around his gravesite seemed less well maintained. Overgrown with weeds, overrun with trash. Fortunately, my father, who died in 2003, did not see any of this. It hadn't dawned on me that Morris' grave was at the edge of the cemetery not just because Morris was not a member of the congregation, but because of his disease. Eventually the disrespect got to me. I wondered, could we move Morris to Arlington



Morris Koll enlisted in the Army at the age of 16 and was sent to the Philippines in 1902 to fight against the insurrection after the Spanish American War. (family photo).

Cemetery and give him the military honors that he had not received in 1938?

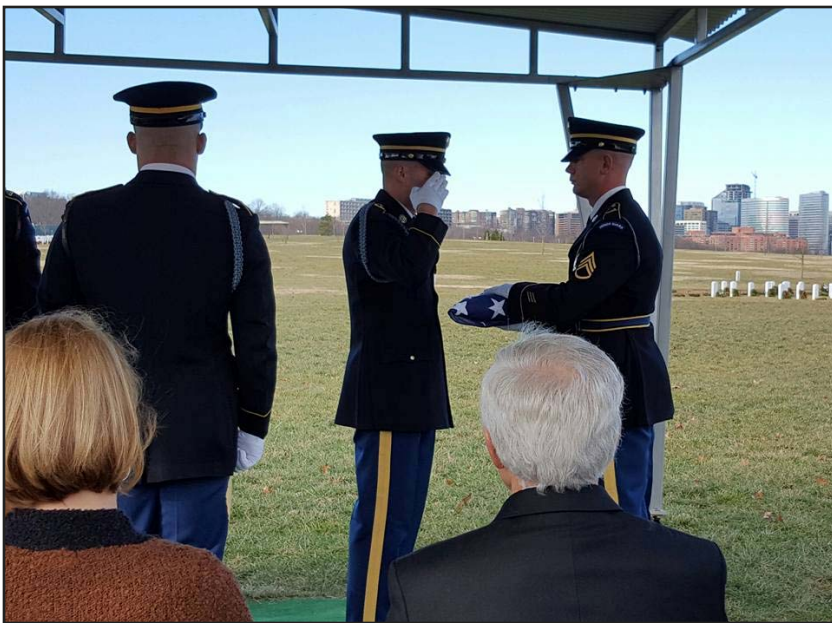
I learned that yes, all veterans are entitled to interment at Arlington, although only cremated remains are accepted today for those who were not officers or killed in battle. So, no burial, but interment in a columbarium was possible. All I needed to do was some paperwork with the various cemeteries, the military, the state of Louisiana, and a majority of Morris' grandchildren, and have Morris exhumed and cremated.

There were outdated military forms I had to track down and verify (like a discharge from 1904). And then, there were the names. Morris was born Morris Kolnitsky or Kolnitzky. Morris had enlisted as an underage boy, using a false name, Morris Kolnsky, the name that was on all of his military records. After the war Morris legally shortened his name to Koll. And at Carville, of course, he went by an alias, Morris Krug.

Establishing that all of these names and documents were referring to the same man took some serious connect-the-dots work, but we finally got there.

So, we made plans to exhume Morris and have him cremated – 78 years after his burial. His remains were shipped to our home near Washington, D.C.

December 27th was clear and crisp, bright blue sky, perfect clouds. Soldiers performed the honor ceremony with utmost respect and dignity, as if Morris had died in service just the week before. A distant bugler played taps. A 21-gun salute. A



Morris Koll received military honors at Arlington Cemetery in December of 2016 when his remains were moved there from Baton Rouge (Photo by Lynne Ganek, family friend).

flag folded and presented to me by an officer on one knee. “Sir, on behalf of the President of the United States, the United States Army and a grateful nation, please accept this flag as a symbol of our appreciation for your loved one’s honorable and faithful service.”

A family stigma replaced by a family honor.

Note from the author: My name, Matthew Benjamin Koll, was given to me in honor of my grandfather. My wife, Pam Fessler promised my father before he died that she would write a book about Carville and the battle against leprosy in America. That book is set to be published as early as next year by Liveright, an imprint of W.W. Norton.

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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 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