

# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

**JULY 2022 -  
DECEMBER 2022  
VOLUME 64 - 32**



## **Julia Rivera Elwood**

**September 1, 1939 - June 26, 2022**

*Photo Courtesy of the Elwood Family*

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### Editorial Policy On Terminology

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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," 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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# My Impressions of Carville

## Julia Rivera Elwood

(Originally published in The Star vol 59 no.3 July-September 2000, this is a slightly edited and shortened version of Julia's remarks)

*(Editor's note: Julia Rivera Elwood was a trailblazer many times over. My introduction to her was made by our mutual surrogate parents at Carville, Darryl and Mary Broussard. She became friends with my girlfriend and later wife Magdalena. She also was loved by my parents and received delicacies from Mexico when my parents would visit me. By the time of my discharge, we had become great friends as Magdalena and I would babysit her children. I was deeply honored when she invited me, one of five former patients, to address the Centennial audience. My comments written on a piece of breakfast napkin became an outline for a lifetime of presentations, and her presence continued in spirit.)*

Before I give my impressions about the many and varied experiences I have had at Carville, as both a patient and an employee, I would like for you to know the way I feel about this place which has represented to me a safe harbor (when I needed a Place to go to be treated for Hansen's disease), an emotional prison (as a result of the stigma which leprosy patients have had to endure) and an emotional challenge because when I was ready to leave, it was extremely difficult.

In my opinion there are not many places in Louisiana which are as naturally beautiful, peaceful, and serene as the grounds of the Center. The sprawling, majestic live oak trees which line the perimeter are the frosting on the cake of the lovely architecture which abounds in this facility. The most impressive and oldest (circa 1857) of the buildings is the extraordinary Indian Camp Plantation Home which was designed by Henry Howard, a prominent architect of the South. The architects who helped design the rest of the buildings now standing, tried to imitate, quite successfully, the grand plantation home features in the Recreation Building. Other buildings which are unusual in architectural beauty are the Sacred Heart Chapel and the



Plantation Home revered by Julia for its architectural influences on Carville's buildings—photo by Tom Adams



Sacred Heart Chapel at Carville  
- photo by Tom Adams

Union Protestant Chapel (many a tear has been shed in these asylum-like houses of God). In addition to the beauty, the government employees did an admirable job of keeping the grounds immaculate through the years.

Besides my family, the people here are some of the unsung heroes in my life. The patients who took me under their wing and decided to be my friends represented caring and sanity to me in an insane situation. Here I was: a 16-year-old terrified young lady in the midst of strangers, away from my family for the first time, overcome with sadness about leaving my family and friends, and scared to death about what seemed a bleak future, not knowing whether I would be able to leave the institution. The Sisters of Charity, whose caring and love kept me from ending it all, were like angels in my hell-like emotional state. The other professional staff played a special part in educating me about Hansen's disease (HD) and mak-



ing sense out of my stalemate life. I love the people at Carville for their warmth and friendship which they have extended to me through these many years, which were sometimes difficult, but mostly successful because they accepted me as I was without wanting to change me. It is to these persons that I am eternally grateful for what they taught me. Some lessons were hurtful, some of them joyful, but all of them made me a better person.

Carville has another extraordinary feature which is a strong aura of the spirit of those who went before us who fought the uphill fight in order to make things better for the patients. The persons who came to Carville in the pre-sulfone era and died without hope of a cure; those who were extremely disfigured for lack of effective treatment; those who lost contact with their families or were rejected by their loved ones; those who cried every night in silence because of loneliness; those who committed suicide; those who lost their identity by taking an alias; the ones who turned to alcohol and drugs to ease their pain; the brave ones who volunteered to be human guinea pigs by taking the newly introduced wonder drugs before and after the sulfones were discovered; and those who were institutionalized and were afraid to face the world after they lived in Carville most of their lives. Some notable friends were those people who were scarred by the stigma attached to leprosy and who were forced to lead secret lives. Other spirits which float around the premises are those of the dedicated Sisters and other staff who cared for the patients with kindness and respect during those difficult times. For those reasons, the [Trautman] Museum must remain open to honor these quiet, brave souls whose spirit will always be in our hearts and in our history.

As I end my tenure at Carville, I have many mixed and varied feelings. As a youngster of 16 when I was diagnosed, I was horrified because I had been forced to leave my loving and close-knit family over 700 miles away. ... For the first time I experienced the stigma which had been attached to the dreaded disease, leprosy, and the separation from family which caused me many days of loneliness, sadness, and crying myself to sleep. As a young girl at the end of my junior year in high school, I had much to look forward to and felt I was robbed of the many rewards and happy memories a senior year brings. I felt as though the end of the world was here and I might as well give up.

When I arrived in 1956 patients received intravenous Promin injections. However, there were still pre-sulfone patients who were disfigured and had multiple handicaps. For an impressionable girl, it was a horror movie that would not end. At the beginning, I tried not to come in contact with the worst disfigured patients, but as I saw them every day and got used to them, they were no longer fearsome objects. In fact, I became a good friend to most of them.

My mind started to change after the first week at Carville when I met "the Youngsters" who were patients close to my age. They were in the same boat, having the same problems as I, and I said to myself; "Maybe I will live after all." In the end, they were my salvation.

I began to join in the activities of the hospital including those spearheaded by Stanley Stein and the Patients' Federation. I remember signing a petition for removal of the medical officer in charge (director) that summer. The patients were tired of the manner in which he ran the hospital, so with the help of Congressman Otto Passman, the petition was presented to the administration of the Department of Health in Washington.

The new director, Dr Edgar B. Johnwick, was a most progressive and kind person. Carville started changing. He instituted the "medical discharge," and the day passes, He also agreed to permit patients to own automobiles and to keep them on the grounds. This was the age of change and many patients used the opportunity to leave Carville and never come back.

In 1959 I married one of the patients at the Sacred Heart Chapel in the Center, one of the first marriages between patients permitted by the administration. My family was not present, but some wonderful people who "adopted me the Carville way," were there to give me away. We were assigned an apartment in House 20 and lived there until 1962, when I was discharged and went to work and live in Baton Rouge. It was tough getting a job, but I asked an employment



*Queen Julia at Carville Mardi Gras - photo courtesy of National HD Museum*

agency to let the new employers know that I had been at Carville and I would not go to work with their company if just one employee objected to it. I worked at a finance company three years and made good friends in the eight employees they had. We moved away to New Mexico, and after a series of separations, and three and a half children later, I found myself pregnant and separated and in my hometown in the Rio Grande Valley.

I consider that one of the hardest challenges of my life, but looking back, it also gave me a determination which I had never experienced in my life. My fourth child was born the last day of 1965, and I went to work 13 days after her birth and worked nonstop (sometimes holding down two jobs at once) and attended college. In 1969, after going to college for three straight years and one summer, and after receiving my degree, I went to work as an English teacher for the junior high students at my alma mater. At that time, I never considered that I might return to Carville to work, but I did. I have worked here now for 29 years and five months and I leave with a warm and delectable feeling of accomplishment.

Many things have changed and improved. Patients did not have to be hospitalized at Carville anymore when they were diagnosed. Several ambulatory care clinics were opened throughout the US. The armadillo model was inoculated. More modern medication was rendered useful in treating HD. Reconstructive surgery was used to restore use of digits. Fewer patients sought Carville as their refuge. Discharged patients went home to stay. Plastic surgery was performed on patients. Aliases were no longer taken by patients upon entering the hospital and those who had them revealed their real names. Patients and staff married each other. Two other former patients were hired as staff at the Center. The LEAP (Lower Extremity Amputation Prevention) program, the Carville Approach, was formed. The Research Lab became an international entity by branching out to research into other diseases. The Center was placed on the National Register of Historic Places. Carville was downsized and spread out into three campuses. The Trautman Museum was opened in its final resting place. I am satisfied.

## **Remembering My Mom—Julia Rivera Elwood**

### **By Monica Elwood Frederic**

I was blessed to be the daughter of Julia Elwood. To know my mother was to love her. The words I'd like to share to honor my mom will never fully capture her life and spirit. She was born one of twelve children to Juliana Farias and Pedro Rivera in the Rio Grande Valley of South Texas. If you knew our grandparents, you understood how mom was so beautifully molded.

My mom was born to simple means, the daughter of a farmer. She never outgrew that grounded simplicity. She was born Catholic and by her teenage years grew to love the Lord with a passion that had her believing she wanted to devote her life to the Lord..... God had other plans for her. Plans that called for a special love and devotion.

At the age of 15, she was chosen as head cheerleader at her high school in Edcouch-Elsa, Texas. During this time her life would take a different turn. Mom was diagnosed with Hansen's disease (HD). Mom was sent to a hospital in Carville, Louisiana.

Mom's first night at Carville Hospital was traumatic. Because of her unsure future and isolation from all she knew and loved, she cried all night. She was held and comforted by a nun named Sr. Estelle, my namesake. Estelle is my middle name.

In 1959 Mom met and married a fellow patient and had 4 children: Mark, Steve, Deborah, and me. The family life she endured was quite differed from the one she was raised in, and this marriage ended in divorce. With only the support of her family, mom returned home, found two jobs and enrolled in college. Her major was another dream of hers, teaching. She finished school in record time and went right to work pursuing life as a teacher.

Life didn't slow down for her. Mom always seemed to surround herself with children in some way. During this time mom had a pregnant family member who was choosing adoption as a parenting choice. Mom's heart and instinct knew she couldn't let a family member be lost to the family. So at 29 years old, with four children of her own, she adopted a fifth, our beautiful sister Jennifer, we all lovingly call Chitty, our caboose!

Our mom never was one to let the grass grow under her feet. She was raising five children, had finished college and was teaching in Texas when she was offered a job back at the second place she called home, Carville, Louisiana, the hospital she was sent away to many years before. There was an opening for a teacher and she was encouraged to apply. She got the job and moved back to Louisiana where she started a career that spanned thirty years. Mom was the first patient



ever to be hired as a federal employee at the hospital.

Mom's role evolved over the years. She was teacher but more than that. This disease was not kind to many patients who ended up at Carville, but mom was always a person you ended up seeking out as a resource, for compassion, as a problem solver, to get a long tight hug, a laugh, or even to get taxes done.

After returning to Carville, mom met, fell in love with, and married our dad, Ray Elwood. Dad came with four children of his own, our bonus family-- Debra, Ray, Tina, and Bert. They lived and were raised in San Antonio but soon became family loved by all of us. Our dad Ray soon adopted the five of us and we became a family of nine Elwood children. This family has grown to include twenty-nine grandchildren and forty-six great-grandchildren, leaving behind a great legacy in their path. That legacy of love is remembered today in mom's handiwork—quilts for us kids, grandkids, nieces, and nephews and for extended family and friends.

Over the years as an employee at Carville mom worked beyond the requirements of the job. She went back to school to earn her Master's degree in English from LSU. She was ready when the position of principal at the Carville school came open. She became principal and the public relations specialist at Carville. She was over the

school, the recreation department, and she always accompanied all journalists who came to learn about Carville. She had a fierce protection of patient privacy and never wanted anyone exploited or photographed and interviewed without their knowledge. **Mom was a huge advocate for changing the name of Leprosy to Hansen's Disease. She was so confident and believed in fairness. Where many patients hid it from people they knew (due to the stigma of the disease), she made it part of her life's mission to spread the word.**

After retiring, Mom and Dad moved to Schertz, Texas, to spend time and spread their love with the San Antonio half of the family. Mom was very active at Good Shepherd Catholic Church. She went to daily mass and both our parents attended Sunday mass. They both brought Eucharist to nursing homes after mass every Sunday and served with other ministries within the church. The food bank being one they enjoyed.

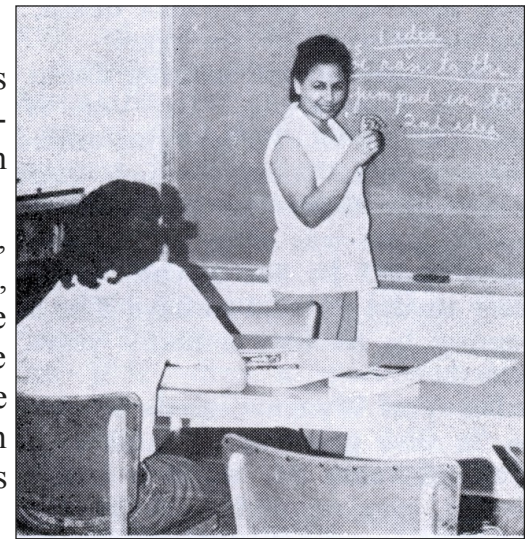
When dad was diagnosed with cancer, mom flew into action. His daily radiation and hyperbaric treatments as well as weekly chemotherapy treatments were no challenge to this "never say stop woman-become nurse." Typical to them, they made friends with other patients and families and mom ended up joining a quilting group that made lap quilts for cancer patients. She participated in this ministry for years and made countless quilts always remembering how cold dad was when he went for treatments.

If mom was anything, she was consistent. She loved well and you always felt it. She always acted with integrity and could be counted on to do the right thing, even if it was the harder thing to do. This was helpful growing up but also led to some disappointment for us in life when we realized not all people are like that. She loved us with food, with her presence, with her laughter, with the spirit in which she did things, and with her support. Over our lifespans, these things have never waivered, her love was unconditional. She defended those she loved with a passion.

I learned from her my love for cooking, for plants, for children, to see the innocence and joy in them, learning, and facing a challenge. This woman would take all of the grandkids at one time and could multi-task doing five things at once without missing a beat. She would be cooking a meal, babysitting, have the kids doing crafts and be quilting at the same time. She would say she was "coulecca" like a hen with all her chicks around her. She loved to have a house full of family and loved to entertain.

She also demonstrated to me the need to pay attention to people when you are with them. She left an impression on those she encountered. I think it was because she was truly mindful and present

Maya Angelou once said, "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." When you were around mom, you always remembered how she made you feel. She made you feel loved. She made you feel like you had a special connection. She made you feel like you were her favorite.



**Julia in the classroom at Carville**  
*Photo courtesy of National  
Hansen's Disease Museum*

## Life With My Mother - Julia Rivera Elwood

By Debbie Elwood

As I reflect on my life with my mother, I can only think of the word "strength". She was always there no matter where our life led us. She was at the doctor if we were sick, at school, at our ball games, band recitals, helping with homework, **always present**. I remember a time where I had surgery and she came to stay at my house to help as I recovered. She was also there holding my hand when I was going through heartache. She showed us her work ethic in her actions. She kept us organized and structured. We ate supper as a family, and she included us in the supper tasks. She played cards and board games with us....and even the outdoor volleyball games. She made sure that we were able to participate in school events and sporting activities. Mom and Dad had a good discipline method and as we got older, we came to appreciate the rules we had to follow.

Family was very important to her and she showed us the rewards of keeping in touch with relatives is. It is funny and cute....the things we saw my mom and her siblings do, we are now doing as adults and loving it.

I remember mom's life at Carville. She was very involved with the patients as their teacher but also as a friend. We remember having parties at the house with friends at Carville over. They would eat, dance, sing, and drink a little. But it was fun to see them have a good time. I also remember the fireworks display that Mom would help pull together and have events like egg toss, sack race, baseball, etc. We still play those games today at our holiday parties. There would be Fishing Rodeo's as an activity at the Lake at Carville. We would attend the Star party and sometimes work the Bingo at the Recreation Hall....all of the events at Carville were so much fun....and my Mom was always behind the scenes making it happen.

We have learned so much from Mom and Carville gave us a perspective that I will always treasure.

Mom had many years of difficulty; she had to leave her home that she grew up in and her family to go to Carville for treatment as a patient. Later she had issues in her marriage with Bill whom she divorced after having 4 children with him. But she always came out of the difficulties stronger and wiser.

Mom had so much faith, she went to church every Sunday and we were right there with her. She was very involved with the choir, eucharistic minister, and taught catechism. Her faith was so great. As I helped take care of her in her last days, we were playing "How Great Thou Art" music and she could not communicate at this time, but as I held her she was humming the tune with the song. She also had difficulties remembering things, but when we sat at her bedside and said the rosary, she still knew the words and said it along with us. She was an incredible woman and so many people say "there is only one Julia" ....there is no other that can compare.

## Julia Rivera Elwood--Trailblazer (1939-2022)

By Claire Manes, Ph.D.

*"You begin to see the soul and spirit" Julia Elwood to Sally Squires*

**Julia, very early in her time in Carville, began to see the soul and spirit of the people. It was this that carried her through her time as a patient and as an employee. Her time as a patient in Carville was painful, lonely, and challenging, but it was also filled with love and support from many. It was this support that motivated her in her return to Carville as the first Civil Service former patient/employee in Carville history. It was her 29 years and 5 months as a staff member that made her a trailblazer with an outsized impact on the community. In 1973 she became the first former patient to be hired.**

Her former teacher Gaston England needed a bi-lingual teacher for the school and remembered young Julia Rivera. Mr. England's conviction of her abilities and MOC Dr. John Trautman's common sense attitude, "If she qualifies, hire her" (Manes) opened the way for Julia's return to Carville. To her dismay, however, she needed to be tested for Mycobacterium leprae. She accepted that test and was hired. She qualified as a bi-lingual teacher and later as a translator on the Star staff.. She was clearly ready to take on the task and title of teacher when she returned to Louisiana with her children.

The position offered unique educational challenges. She instructed students of different ages, ethnicities, and languages. They attended class with different needs, interests, and abilities; staff members wanting to learn Spanish also



joined Julia's classes. Despite her excitement over the challenges, she admitted to Sally Squires in 1997, there were trials, too. Not all staff or patients were comfortable with a patient as a staff member. She had figuratively "crossed the hedge," the dividing line between staff and patients, and she had changed protocol, but "some of the patients (and staff) were looking for me to fail." Surprised but undaunted, Julia remained true to her intention, "I was here to prove something. I wanted the patients to know that a patient can do this." (Squires)

Her personal life was enlivened when Ray Elwood, a returning patient pedaled to the school from the Star office to eat lunch with the "new teacher." They were soon married and set about uniting their two families. Throughout their almost fifty years of marriage, family was their priority even as they gave themselves fully to the Carville community. Julia's daughter Monica recalls that her mother never forgot birthdays, Valentine's day, Christmas for her children, grandchildren, nieces and nephews.

When Gaston England retired, Julia, who had earned a Master's degree in School Administration from LSU, became principal and head of the public relations office for the facility. Dr. Trautman declared her "the best damned PR person the hospital ever had." (Manes) Julia's heart, enthusiasm, and passion were key to her success. Words like "kind," "generous," "a true friend," "a hard worker" "a blessing" "courage," (remarks on Friends of the Carville Historic District Facebook page) have been written about her. Those skills and traits did indeed make her the right choice for PR. She had lived on both sides at Carville and drew on that experience when working with patients, staff, and outside visitors.

She had lived, prayed, cried, suffered, and celebrated with the patients. She knew personally the pain and isolation of so many especially old timers and she could empathize with their needs. Anne Harmon Brett recalls "She could be gatekeeper for so many as well." Anne shared stories about Julia and her father, Johnny Harmon, who for the most part relished interviews and contacts with reporters. Julia knew Mr. Harmon's interests but also his limits with a curious public and she could deftly negotiate his visitors. She showed the same sensitivity to all patients protecting their privacy and wishes whenever the need arose.

She knew the staff; she had been helped and treated by them and she had been on staff herself. Consequently, she was able to address their stories as authentically as she could those of the patients. The Daughters of Charity had supported Julia as a young patient. She maintained a deep love and respect for these women who had given their lives in service.

It was Julia's lived experience that fueled her love and passion for Carville. When she welcomed visitors, organized meetings, toured reporters, supported family's looking for stories about their relatives she was sharing not a script but her life and the life of so many others. Her love for Carville was evident in the remarks she made at the opening of the museum in 2000 reprinted in part in this issue as "In Her Own Words My Impressions of Carville."

While there were multiple accomplishments for Julia during her tenure at Carville, three events stand out and speak to her passion for telling Carville's story: celebrations of two hospital centennials and the opening of the museum. All events were testament to Julia's knowledge of Carville's history and her love and conviction that that history deserved celebration, preservation, and a wider audience.

In 1994 Julia and her committee organized a week-long commemoration for the Carville Centennial. Her efforts culminated in the celebration itself as well as a written publication and video program "Known Simply to the Rest of the World as Carville" detailing the history of HD and Carville.

Hardly catching her breath after the 1994 celebration, Julia began plans for a daylong celebration of the arrival of the Daughters of Charity in 1896. Julia's faith connected her to these women who like her had broken barriers. To celebrate and honor the community, Julia penned a second publication, "With Love in their Hearts," tracing the religious women's history and contributions to the patients and the hospital.

Left with memories and mementoes from the two celebrations, Julia envisioned a museum to hold these treasures, educate the public about HD, and honor the Carville story. Julia's service at Carville ended with her retirement and move



**Julia aside Dr Jacobson at museum dedication**  
*Photo from The Star, vol 59, No. 3*



to Texas. She spent time with family but continued to support the Star with her column “Colorful Characters at Carville.”

There could have been another PR person; someone else could have done the job. Party planners could have organized celebrations, but no one could have accomplished these tasks like Julia. As a scared 16-year-old she saw the “soul and spirit” of others and she spent her life serving and honoring the humanity she had seen in tired eyes and ravaged features. Julia Rivera had been elected as the first Mexican American head cheerleader at her high school. She never served in that capacity, but Julia Rivera Elwood, daughter, sister, aunt, mother, grandmother, great grandmother, patient, teacher, principal, Public Relations director, and trailblazer, gave herself and her spirit to make sure that others knew what she had known for years—the humanity, soul, and spirit in Carville!

*EDITOR’S NOTE: Julia’s surrogate parents were also assigned to me upon my admission. Similar to Julia, I, too, was abruptly removed from my family so we established an admiration for each other. My wife and I would double date with her and Ray and on occasion would babysit her four children now adults who along with Ray’s adult children emulate Julia’s compassion for others and Ray’s willingness to help all in need. (José Ramirez)*

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## Remembering and Valuing the End of an Era by Claire Manes, Ph.D.

An era of pride and pain ended on July 17, 2022, when Jose Azaharez died at St. Clare’s Manor in Baton Rouge, Louisiana. Mr. Azaharez was the last permanent resident of the Carville hospital and St. Clare’s Manor. No longer are HD patients confined to a hospital or isolated from family.

Jose Azaharez was memorialized and buried under the pecans at a service in the Carville cemetery on July 21, 2022. According to José Ramirez’s recollection, Mr. Azaharez and other Cubans were exiled to the United States in 1968 because of Hansen’s disease. From 1968 until his death the Cuban born Azaharez had been a resident of Carville and later St. Clare’s. Ramirez recalled that Mr. Azaharez had been a talented boxer in his home country. Remembering the Cuban boxer Jose recalled Azaharez’s stories about training with Teofilo Stephenson who became only one of three boxers to win three Olympic Gold medals, the first at Munich in 1972. Jose relates that HD had crippled Azaharez’s hands but did not destroy their power. “He used his hands during sermons, reaching up to the sky, the ‘home of God.’” Staff and friends who remembered him in later years described a “dapper man,” “quiet spoken” but sure of his own truth and opinions.

Ms. Geraldine Refuge, a Carville staff member, care giver for Jose, and, above all, his friend recalled the years of their friendship. She would help him with his grocery shopping; he helped her with her garden. Ms. Refuge, too, acknowledged him as a deeply religious man.. They would attend church services on Sunday then share a meal together. In 2003 Jose achieved a new level of ministry when he graduated from a ministerial program. The memorial booklet for his funeral service displays the picture of an older gentleman in 2003, wearing a blue graduation cap and gown. In the picture he proudly displays his ministerial diploma. Armed with his deep faith and his ministerial credentials he continued his prayer ministry. He regularly served those in the Ascension Parish prison and at St. Clare’s Manor.

Jose Azaharez’s death marks the end of an era—the one hundred twenty-eight years of the Carville facility. Those who lived and died in the facility can be honored by assuring that fear and ignorance never again incarcerate or stigmatize folk. While fear should never again create an institution like Carville, we would be remiss if we failed to remember and honor the great gifts that emerged from the hospital. We keep in memory Dr. Isadore Dyer who sought care and treatment for Hansen’s disease patients; the Daughters of Charity who lived with and cared for patients for more than 100 years; the Federal staff who made Carville a world class hospital; and the local community who worked and served on the premises. We recall Stanley Stein and the Star that radiates the truth about HD even today and Dr. Guy Faget and the patients who contributed to the miracle at Carville. Finally, we remember the men, women, and children who lived the life they had been dealt with dignity and grace. Carville Hospital should never be repeated but never forgotten.

# My Personal Journey with Clofazimine: A Tale of Separation

By José Ramirez, Jr.

In the last issue of The STAR, I shared my journey to Carville, and one of the experimental medications (Thalidomide) I took in 1968 in an effort to lessen my ENL (reaction or Erythema Nodosum Leprosum) from Hansen's disease (HD). For this story, I would like to describe my experiences with another experimental medication, first introduced to me in 1969 as B633. This was Clofazimine, discovered in Trinity University in Ireland as a treatment for tuberculosis (TB), and later for HD and complex lung disease.

In 1969, the pharmaceutical company of Novartis commenced selling the same drug as Clofazimine (Lamprene) for the treatment of Hansen's disease (HD). In 1983 the Orphan Drug Act was passed in the U.S., formally allowing pharmaceutical companies to manufacture drugs that have limited potential for profitability, but which are valuable in the treatment of certain diseases. In 1986 the Federal Drug Administration approved the use of Novartis' Clofazimine. The use of Clofazimine for HD preceded the Orphan Drug Act of 1983 by 17 years.

**In some cultures HD is referred to as the “separating sickness.” It was that for me. My previous article described a journey with HD that commenced many years before I was diagnosed. As referenced in that story, I was abruptly removed from my family literally overnight. However, I had experienced many painful separations years before I was separated from society and institutionalized for seven years.**

In 1963, my hometown of Laredo, TX had only one high school, joined by students from two junior high schools when promoted to the 10<sup>th</sup> grade. That year, the Laredo Independent School District approved the building of a new high school and established boundaries for who would attend which school. Ironically, my parents cheerfully informed their 13 children that they had finally secured financial approval for the purchase of their first home. The home, with a large back yard, was on what then was the outskirts of Laredo, but within the boundaries of the new high school. Previously we had lived in rentals and a housing project and I would not have been in the new school boundaries.

So, going into the 11<sup>th</sup> grade, I was required to attend the new high school. My sister Diana, a senior, was allowed to stay in the old school. My girlfriend too, stayed in the same school. My participation in sports, especially football and baseball, meant that I would compete against lifelong friends from the opposing high school. Such a separation from schools created both laughter and sadness. Diana was chosen head cheerleader of her school, and Magdalena was the Lieutenant Colonel of the Pep Squad and Colonel in JROTC (Junior Reserve Officer Training Corps). The end result was that during football and baseball games there was an aura of separation as both cheered against my team. To this day, Diana and Magdalena remain strong supporters of their high school “Tigers” and I of the “Mustangs.”

Another separation was when my still unknown illness caused two younger brothers, Javier and Rudy, to alternate sleeping on the living room couch or floor. Ever since we were children, the three of us had shared one bed, for obvious reasons, we were seven boys and six girls. Being the oldest of the boys, I was automatically granted the choice of what part of the bed I slept on. I would always choose the side closest to the window. The evenings in Laredo would always end with a soothing and cooling breeze that was an escape from the dry heat of the day that would often top 100 degrees F (37 degrees C) during the summer months.

My recollection was that for years I had experienced periods of fatigue, fevers, unexplained pain and nodules that resembled very large pimples. After high school these periods became more frequent. My body became progressively more tender and painful to the touch. My brothers would notice my grunts as I would try to gingerly get to my spot by the window. I typically would be one of the last ones to go to bed as I would finish my college homework or return home from my part time job as a dishwasher. My brothers would not mention anything to me, but they did tell mom.

The pain became so overwhelming that I could not continue my part time job, education at Laredo Junior College, nor go on dates with Magdalena. My brothers volunteered to stop using the bed and we were separated from our life long ritual of sharing a bed.

The nodules became bloody and mom delicately changed the sheets. I had grown weary of going to doctors who kept misdiagnosing my illness, so I refused any further visits to a MD. When I finally capitulated and gingerly walked to the family car for a trip to Mercy Hospital, I did not have confidence that a diagnosis would occur. Surprisingly, within 24 hours the Director of the Texas Health Department was at my bedside to share my diagnosis and inform me of my trip next day to a hospital in Carville, Louisiana-----separation.

At Mercy Hospital I was placed in a room designed for two patients. As soon as the Center for Disease Control

notified my MDs of the results of a hand biopsy, my roommate was quickly removed and I was placed in isolation. Petrified as I struggled to prepare for the unknown, I sought solace and asked my mother to have someone stay with me the last night at Mercy Hospital. My oldest sister, Yolanda, volunteered to stay. She gently held my hand all night as I tried to hide my tears and fear.

Sacrifices by Yolanda, Diana, Javier and Rudy were followed by many others as I was taken out of Laredo to Louisiana. The separation from family was extremely traumatic for me as I would contemplate ways to escape from loneliness: physically, emotionally, and spiritually. Other patients, as old as my parents, were constantly watching me to prevent any repeat of a suicide by one of the patients. Luckily, they kept me separated from the dark side of this grossly misunderstood disease.

The separation continued for many years as milestones, accomplishments and funny incidents were reached/experienced by my siblings. Even today I cannot relate to some of their memories which bring much pleasure to them.

As my stay at Carville became longer, my ENL continued. Another medication prescribed which helped me with pain and prevented further physical scarring was Clofazimine, a brown pill. I had seen other patients who had agreed to take the medication. Their faces became darker, even for those that were black. Others had an uneven discoloration on their faces. All were reluctant to be seen outside of the hospital grounds but all shared how their ENL had subsided.

As was the case with Thalidomide, my parents had to grant written permission for me to commence taking Clofazimine. The medication, taken with dapsone, prednisone and thalidomide, started to take effect quickly: turning my complexion darker than many black staff members, darkening my stool, generating extreme constipation to the point of needing enemas on a regular basis, affecting my eyesight (need for glasses and regular checks by Dr. Margaret Brand, eye specialist), and mood swings (which I did not recognize). All of these symptoms continued for a long time after I stopped taking the medication.

The darkening of my skin occurred at a unique time during my stay at Carville. One, the Chinese patient who would serve as barber for many patients refused to cut my hair in a crewcut manner as I was used to. He felt such was “unnatural” and suggested “more hair” on top, giving me a facsimile of an Afro, a hairstyle that was immensely popular in the black community at the time. Two, I had just been approved for continuing my education at Louisiana State University in Baton Rouge, Louisiana. Attending LSU in the late 1960’s with my dark features and small Afro, in a sea of white faces, heightened my senses of fear and sound behind me. I learned to block out, as much as possible, the footsteps behind me and the accompanying derogatory comments related to, and using the N word.

Semester registration at the time was comprised of a long line of tables with a specific task for each. It started with collections in cash or check for the classes previously assigned by studies. This was followed by the collection of books or vouchers for book store pick up for each class, the high drama of fraternities and sororities and finally, the different clubs in need of new members and their dues. The walk, for me, along this lengthy row of tables was a parade of ugly stares and dehumanizing comments, “Next table N.”

The insults did not end at registration, but continued throughout the semesters I attended school as I walked the campus from class to class. The Grand Dragon of the KKK and his entourage were regular followers of my footsteps. The racial comments came from both males and females. I was often referred to as “boy” by campus police. I was separated from the school community, and felt the same way in the larger community. Denial of service at convenience stores extended to large department stores. The local police often stopped me, asked for my driver’s license, and wanted to know where I was going, or coming from, while keeping his hand on his gun. This experience with the police made me change my driving habits as I avoided driving at night as much as possible. I did not share these incidents with my parents as such would have added to their constant worry about me.

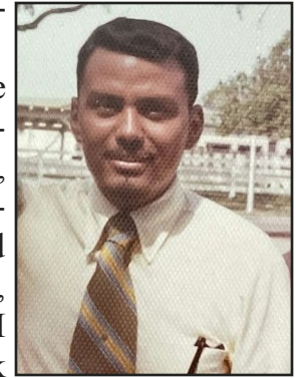
During these times as a patient at Carville and a student at LSU, I encountered instances of rejection as others found out I was a patient at Carville. Racism, due to having a dark skin, would suddenly stop. My heritage also added to the feelings of separation. The aggressor of racism would look startled as they heard my accent. Considering that my first language was Spanish, there is a recognizable tone to my voice, though I have been told that I “am not difficult to understand.” In Louisiana during the 1960s the population was not used to outsiders. One was either black or white and in the eyes of others, I was neither.

Two places where I felt at ease with the color of my skin was at the hospital, and on the campus of Southern University (SU). The university with an ocean of black faces was the opposite of LSU with a sea of white faces. Driving to



the SU campus, I was stared at, without remorse, called out as a “n.” Once inside the campus I was referred to as “Hey ‘Bro.’”

While completing my graduate studies at LSU I met Dr. Demetria McJulien, the Director of the SU undergraduate social work program. Our meeting occurred after the conclusion of a LSU sponsored social work seminar where I questioned why courses on “minorities focused only on blacks, omitting Asians, Latinos and Native Americans.” Dr. McJulien challenged me to address such a discrepancy in a course titled “Social Work for seniors” at SU. Reluctantly I accepted the challenge and was hired as adjunct faculty after my graduation from LSU. I felt very proud of such an opportunity, looking forward to teaching students about minorities not restricted to blacks. My pride exploded as I quickly became the student. I was introduced to the opposing views which navigated through the black community.



**José at LSU graduation with ever-darkening skin**

With Clofazimine, I learned about the physical separation from family, the emotional and spiritual separation from the broader community due to the stigma welded to the only disease referenced in the Bible, as well as the realities of separation by the color of one’s skin.

As I separated from my life as a patient at Carville, I left a rich man, emotionally and spiritually, feeling enhanced by love for my family, appreciation for those labeled and rejected, and respect for the millions who have been confronted with the HD bacillus, and its accompanying sibling, stigma.

Now, as I reach the end of my professional career as a Licensed Clinical Social Worker, I realize I have come full circle with Clofazimine. Working in heart and lung transplant services at the Houston Medical Center, I have discovered that Clofazimine is used to treat a rare lung disease, Mycobacterium avium complex (MAC). Luckily, the persons prescribed this medication do not have to face the challenges of separation and labeling so prevalent in the 1960’s.

My brothers and sisters throughout the globe can benefit from the availability of Clofazimine to dramatically lessen their physical pain. The emotional pain can be triggered by individuals, innocently or intentionally, taking actions or using words which label us. Those of us who have experienced HD learn that such labeling does NOT define us, or me. We continue to fight this stigma: an act of labeling, rejection or unexplained fear.

## The Forty and Eight’s Marker Restoration Effort

**By Tom Adams, R.Ph.**

The first 137 Hansen's disease patients who died at Carville between 1895 and 1922 are not interred at the current Carville Cemetery. Their final resting place lies in Carville’s first patient cemetery located in the front quad of the patients’ dorms with no headstones or grave markings of any kind. In June 1922 a granite monument bearing a bronze plaque with the patient numbers and names of the 137 was erected near the gravesites.

The bronze plaque no longer has the clean appearance of the 1950's photograph, but instead has naturally bonded with the atmosphere over time giving it a distinctive dark green patina. Also, the monument's granite is a casualty of the rain and sprinkler water that has caused a heavy deposit of salt efflorescence along the base of the bronze plaque. So, both the plaque and its granite support are candidates for essential restoration. A Special Project Forty and Eight project titled "2023 Monument Restoration" funds the effort to address restoration of the plaque and its granite support and insure remembrance of the 137 patients at their final resting place.



**Patient points cane at 1922 Monument, still shiny bronze in this circa 1950 photo courtesy of the National Hansen’s Disease Museum**



**Monument with green patina and salt efflorescence of granite - Photo by Elizabeth Schexnyder**

Donations are needed to cover the cost of the restoration. Checks made payable to "Carville Star Program" and designated "for 2023 Monument Restoration" are encouraged and should be sent to Tom Emerson, 615 W 3rd Ave, Garnett KS 66032.

## Another Gentleman Behind *The Star*

By Tom Adams

### Employment at Forty and Eight

On 15 September 1984 the Forty and Eight made perhaps its most important staffing decision in the history of the organization when William (Bill) Beaumont was hired as an office manager with information technology responsibilities. As a 1983 graduate with a Bachelor's Degree in Business from Indiana University, Bill's duty was to maintain the mainframe computer that supported the Forty and Eight's headquarters in Indianapolis. Like many others who began their careers in the early days of information technology, Bill's job rapidly evolved and expanded in scope as the Forty and Eight recognized the need to employ the power of computers to simplify many of the mundane tasks associated with maintenance of membership records, tracking of dues, production of mailing labels, and much more. To fulfill an expanded job description that included these tasks it was initially necessary for Bill to write software in Computer Business-Oriented Language (COBOL). By 1998 the advent of Local Area Networks (LANs) enabled Bill to guide a migration from the mainframe computer to Windows-based computing, ultimately setting the stage for his role in publishing *The Star*.



Bill Beaumont

### Publishing *The Star*



To better appreciate Bill's role in publishing *The Star* it is helpful to examine the history of how *The Star* progressed from the "pens" of its contributing writers to its readers across the globe. The iconic cover of the December 1943 edition of *The Star* illustrates an airplane flown by Santa dropping a printing press at Carville as a Christmas gift from the Forty and Eight. Inside this edition of *The Star*, columnist Ms Ann Page writes "We, of *The Star* staff know there is a real-life Santa Claus. He may not have a long white beard and a sled with reindeer, BUT he certainly delivered that long looked for printing press. Cheers for the 40&8... We can't help but succeed in our work with you fellows behind us." A printing press meant that *The Star* could be printed by the staff at Carville instead of mimeographed. The June 1944 edition of *The Star* became the first printed edition. At its peak, the printing and preparation for mailing was performed by a robust staff of upwards of 40 Carville patients.

In the January 2006 - June 2007 edition of *The Star*, Correspondant Nationale David Rabius noted that without patients at Carville *The Star* could no longer be printed and prepared for mailing at Carville. Rabius determined it was time for *The Star* to enter the "electronic age" and he called upon Bill Beaumont to make it happen. Bill input articles into commercial software for this January 2006 - June 2007 edition of *The Star* in a format that continues today as the standard for *The Star*. Additionally, Rabius instructed Bill to make *The Star* available "electronically" on the Forty and Eight website making it readily accessible worldwide.

In a 2011 edition of *The Star*, Ray and Julia Elwood wrote of "The Gentleman Behind *The Star*," in reference to Stanley Stein, managing editor of *The Star* from 1931 to 1967. While no one's accomplishments will ever compare to Stein's, nonetheless for the last 16 years there has been another "Gentleman Behind *The Star*" whose commitment has insured the timely publication of a quality product. As a "staff" of one person (with many job responsibilities other than *The Star*), for each edition of *The Star* he received the input of authors, introduced it into software, put it into a visually pleasing format, and passed the resulting product to a printer for printing and preparation for mailing. It is notable that Bill's important role has not been routinely recognized or credited within *The Star*.

Bill resigned from his Forty and Eight employment in 2020 to pursue other opportunities, though since then he has been an independent contractor with the Forty and Eight allowing him to continue his role in publication of *The Star*. With this edition, his service to the Forty and Eight ends. Though he can never be replaced, publication of *The Star* will continue, constantly striving to meet the standard Bill has established. The Editorial Board of *The Star* wishes Bill Godspeed and continued successes in his life's journey.



**Carville Grounds Ring  
with the Return of Friends  
By Claire Manes**

The grounds of the former Gillis Long National Hansen’s Disease Center now the domain of the Louisiana National Guard rang out with chatter among friends and sizzled with hamburgers and hot dogs on the grills on October 28, 2022. The National Hansen’s Disease Program in Baton Rouge reprised its first fall get together since Covid and for the first time celebrated at Carville.

Through the graciousness of the Baton Rouge staff and the help of Elizabeth Schexnyder, curator of the National Hansen’s Disease Museum, invitations were extended to retired workers, former patients, members of the 40 & 8 and the families of some former patients. The museum, the Catholic chapel, some walkways, and grounds were open for visiting, photographing, and remembering.

There were endless conversations, hugs, friendly teasing over the pie competition and food, food, food. But deepest of all, the most important ingredient of the day was the love and camaraderie of people who valued Carville and its mission and who were there to celebrate.



Carville Star Program Director Tom Adams meets and reminisces with Ray McPherson who served as Carville's Protestant Chaplain from 1975-1999

**A Christmastide reflection from the  
December 1947 edition of The Star:**

Modestly, humbly, diffidently, The Star dares an analogy. The Star has brought Carville to the attention of a nation with its avowed mission of “shedding the light of truth on Hansen’s disease.” May those who have followed The Star thus far imitate the wise men of two thousand years ago, and, in their own communities spread the truth that The Star has brought them. Be a wise man. Follow The Star. - Sister Catherine

**Coming in the Next Issue of The Star:**

The next Star will feature the Twenty-first International Leprosy Congress held in Hyderabad, India. The Congress highlighted many new developments in HD research and other important matters.

Also planned for the next issue is coverage of the pre-Congress meeting of the Sasakawa Foundation where many concerns of persons who have experienced HD were addressed.

**\*\*\* ATTENTION \*\*\***

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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.

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