The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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Mr. Perry Enriquez arrived at Carville in 1936

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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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On July 11, 2008, **Mr. Perry Enriquez** celebrated 100 years on earth. When Mr. Perry arrived at Carville in 1936, the hospital was a collection of wooden, single story buildings and chaulmoogra oil was *the* only treatment for Hansen's disease. He told me of taking painful injections three times a week (5cc in the buttocks and 5cc in the arm) and how he had a job in the laboratory with Dr. Pogge filling huge syringes with the viscous oil.

Last month Perry had a visit from Ann and Carol Faget, grand daughters of Dr. Guy Faget, Medical Director in Charge from 1940-47. The Faget's wanted to talk to Perry as a bridge to their famous grandfather. Perry remembered Dr. Guy Faget as "the little doctor" who instituted the first clinical trials of Promin therapy at Carville in 1941, a.k.a. *The Miracle at Carville*. Mr. Perry counted the U.S. moon landing in 1969 as one of the most amazing events occurring in his life. It was thus noteworthy that Guy's son, Maxime A. Faget, (the sisters' father) was Director of Engineering and Development at NASA and contributed to the design of all of the Mercury capsule, as well as the later Gemini and Apollo spacecraft and the Space Shuttle.

Mr. Perry was born in St. Vincent, on Luzon Island in the Philippines, one of seven children. Two brothers were killed in WWII fighting in the Philippines. Perry completed 8 years of school, learning some English in the process, but then he had to go to work. Simeon (known as *Pepe*) now in his 80s, is Perry's only surviving sibling.

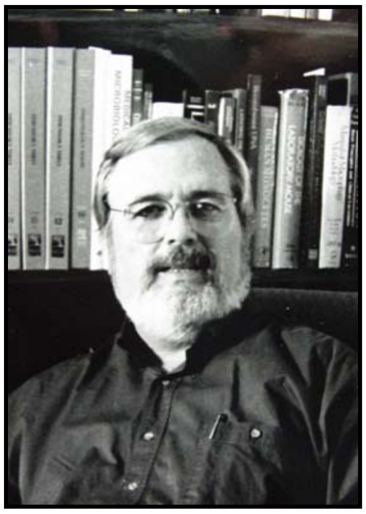
Immigrating to the United States in1926 involved a month long journey via steamer ship. In California, Mr. Perry found work in the agricultural industry. He was already married to his first wife, Maria, when he was diagnosed with HD. But the prospect of Carville did not frighten him. He knew he could get the best medical treatment possible here.

He adjusted quickly to life at Carville, but remembers having difficulty, with quarantine. He admits "absconding" in the 1940s when his first daughter, Theresa, was born. Later another daughter, Delores, joined the family. "I worked hard to raise my daughters and to put them through college; I wanted them to be educated," he told me proudly. The family now includes a granddaughter and grandson and two great-granddaughters.

Maria died in 1984 and Perry returned to Carville. Quarantine as a policy was long past with multi-drug therapy the treatment of choice. In 1985, Mr. Perry found love again and married Juanita. He inherited her position as librarian. He displays a US flag over his desk; a framed photograph of President Bush sits on a bookshelf. "I am proud of my country," says Perry, who exhibits his framed US citizenship papers in his room.

"Scratching the guitar" and singing are Mr. Perry's favorite pastimes. Anyone who has heard Perry belt out "New York, New York" or "I Left My Heart in San Francisco" can attest to his lungpower. During his earlier hospital days, he was a regular performer in Sr. Laura's Christmas Cantatas and sang in Sacred Heart Chapel's choir. Perry Como, Frank Sinatra, Tony Bennett and Tom Jones are some of the crooners who inspire him.

He laughs when I asked him for words of wisdom, saying he never thought he would make it to one hundred years old and accredits "no drinking and no smoking" as the path to longevity. Happy one-hundred, Mr. Perry, and many, many more! *******



James Krahenbuhl, Ph.d., Director, NHDP

Dr. Krahenbuhl was born in 1942 and raised in Menasha, WI. He received his B.S. (1964 – Zoology), M.S. (1967 – Medical Microbiology) and Ph.D. (1969 – Medical Microbiology) from the University of Wisconsin in Madison. He did his postdoctoral work (1970-1972) in Infectious Diseases at the Stanford University School of Medicine in Palo Alto, CA studying opportunistic pathogens in the immunocompromised host. From 1972-1979 he was a staff scientist at Stanford and the Palo Alto Medical Research Foundation where he was awarded several NIH (National Institute of Health) and NCI (National Cancer Institute) grants for studying immunotherapeutic measures for treating cancer. He also received a 5 year Career Development Award from the NIH. Dr Krahenbuhl's background in investigation of host cellular immune mechanisms in infection and cancer qualified him to take the position in 1979 as Chief of Leprosy Research at the U.S. Public Health Service Hospital on the Presidio in San Francisco where he served until 1981 when the USPHS Hospital system was closed. He returned to Stanford as a visiting scientist continuing leprosy research and in 1983 relocated to the Gillis W. Long Hansen's Disease Center (GWLHDC) at Carville, LA as Chief of the Immunology Research Dept in the Laboratory Research Branch (LRB). In 1990 he received the Health and Human Service Secretary's Distinguished Service Award for Biomedical Research. In 1992 the LRB relocated to the LSU School of Veterinary Medicine and in 1994 Dr. Krahenbuhl became Chief of the LRB. The GWLHDC relocated in 1999 from the Carville site to the Ochsner Medical Center in Baton Rouge and became the National Hansen's Disease Programs. Dr. Krahenbuhl became Director of the NHDP in June of 2005 but maintains a small research program at the LRB at LSU.

Stigma: An Editorial

by José Ramirez, Jr.

Stanley Stein and others have passionately written about the negative effects of the “L” word – “leper,” mentioned here once and never again – and the associating stigma that it creates. The “L” word can easily outdistance four letter words in negative impact. Even when spelled in reverse – repel – it forms images and shades of dislike.

Leprosy is the most often mentioned illness in the Bible, but it is its evil twin, the “L” word that routinely elicits fear, and rejection of those affected by this illness. Unfortunately, the mindset of many throughout the world is that the use of the “L” word in the Bible and other historical documents justifies the use of this word in routine conversations. This argument has no merit, just as the use of the “n” word to describe African Americans, “crazy” those with chronic mental illness, and “moron” to refer to those with mental retardation have no merit.

Persons working in the field of leprosy agree that stigma does exist. However, there are still some active in the world of leprosy, who believe that self-stigma is more prevalent than stigma. They usually base their conclusions on “scientific evidence,” i.e., it is difficult to uniformly measure stigma because of the vast differences in geography, boundaries, cultures and languages where HD is found. This belief in self-stigma is in itself stigmatizing as the labeling of persons affected by leprosy continues to be so even in the year 2008.

One must understand that stigma has a long history. My definition of stigma is “an act of labeling, rejection or unexplained fear of a person.” This definition is based on over 30 centuries of the use of the “L” word or facsimile; more than 70 generations of societies who have defined those of us affected by leprosy through the use of the “L” word; and the description of persons affected by leprosy via a word equal in harshness to the “L” word in all of the world’s 42 major languages.

So, if the “L” word is so pejorative in meaning, why do so many continue to use this term? The reason is that it is a simple word to use to convey a powerful message of failure, insult, and imagery. The media uses it to describe persons who have been disgraced. Novelists use it to reference losers. Athletes use it to describe their feelings of getting caught cheating. Religious leaders use it to emphasize sin and punishment. The general public uses it to degrade self or others.

Stigma in leprosy is not going to be eliminated in my lifetime nor in that of the readers of the Star. However, one at a time we can make a difference. We can do this by attacking leprosy-related myths one at a time. These actions can change attitudes, lessen unfounded fears and broaden the empowerment base of those of us affected by leprosy.

The world must understand that we are not simply a harsh label that brands our existence. We are brothers, sisters, mothers, fathers, aunts, uncles, grandparents, artists, mechanics, writers, teachers, social workers, role models, advocates, and much more.

Once this is understood, and accepted, stigma can be reduced, our voices heard, and our dignity and respect restored.

“My eye-opening trip”

by Erika Ramirez

For as long as I can remember my Dad has been working with various organizations to help fight the stigma of leprosy. He has made trips around the world to speak- Japan, Turkey, Ukraine, Spain, Brazil, and many more, usually with my Mom by his side. Often, my involvement was nothing more than a viewing of his pictures and stories of how the trip went. It was not until this year that I finally got the opportunity to accompany my Dad did I get realize the impact he really makes.

My opportunity came soon after I returned from my internship in California at the U.S. Olympic Training Center (I had received my degree from the University of Texas). It just so happened that I would have the rare chance to travel this time with my Father. My older brother, J.R., had been with him to the Ukraine to conduct some oral histories on persons affected by leprosy. It was now my turn. We would travel to London, and then to Hyderabad, India, for the 17th International Leprosy Congress.

Our first stop in London was for the signing of the 2008 Global Appeal to Eliminate Stigma and Discrimination against people with leprosy. It was enlightening to see a mixture of very respectable people- philanthropists who were putting their position in life to a good purpose. I enjoyed talking to many who had heard my Dad speak before. My eyes began to open up to the impact he had been making.

However, it was not until we got to India that I truly realized how involved he had been over his lifetime. He greeted people with hugs and a big smile on his face, constantly referring to others as his brother or sister. It was nice to see this side of him, as it was really something special. He seemed truly happy to be at the Congress, and looking forward to making a 2 two-hour presentation he had worked on so diligently for weeks. I began to meet all of the people he had talked about in the past- most asking for my Mom, as they had grown accustomed to them traveling together. He had established a close bond with many persons from all over the world.

The day before my Dad's first presentation, he found out that he would in fact be making five 15-minute presentations. Instead of getting mad at himself for working so hard on his 2-hour long presentations and only speaking for 15 minutes, he was instead happy, saying that at least he'd have information for future engagements.

With my computer knowledge, he was able to shorten his Power Point presentation. During his speeches, I helped pass out displays of chamoogra seeds and Diasone prepared by the National HD Museum (Carville, La.) in bottles that were replicas of those used in the 1940's when the cure for leprosy was first used. I liked being involved, and I liked seeing people come up to my Dad telling him how much they learned from his presentations. I even got to see him gracefully handle a situation when a doctor, who presented right before him, kept using the five letter "L" word. Instead of getting angry, he calmly handled the situation and instead chose to educate her and the audience about the stigma associated with the word.

His trips of the past no longer seemed like distant images- instead, I was involved, and it felt nice to see this other side of my Dad. I enjoyed seeing people from all over the world with this great passion for overcoming stigma.

In the end, I'm very grateful to have had this experience. Sometimes it takes an outsiders' point of view to see the impact that someone is really making. Now that I have a clearer perspective, I plan to continue my involvement with Dad, and hope to help him promote his autobiography, which is set for release later this year.

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Ninth Meeting of the WHO Technical Advisory Group on Leprosy Control, Cairo, Egypt 6-7 March 2008

On March 6-7, 2008, I had the unique opportunity to attend the World Health Organization's Technical Assistance Group (TAG) meeting in Cairo, Egypt. It was unique because it was the first time that this distinguished group of experts in the field of Hansen's disease had included in their agenda a presentation by a person affected by leprosy. Additionally, Dr. Pannikar of WHO suggested that I make a presentation on stigma. The meeting was structured in a way to allow for maximum input in various areas of leprosy from all parts of the world. The recommendations listed below is the outcome of the meeting, many of significant importance, such as the discontinuation of the use "eradication" when discussing this illness; the importance of co-infection in HIV/HD affected persons; mode of transmission of the illness; and global research on the topic of stigma. These recommendations will be discussed by many world-wide, with WHO addressing some of these areas as new or expanded strategies. -José Ramirez, Jr.

Conclusions and Recommendations

The TAG noted that while leprosy appears to have declined in many populations, the disease remains endemic in a number of countries. It is recognized that the interpretation of routine data is difficult because of the important influence of operational factors which differ greatly between countries.

Further efforts are needed to improve the quality of routine case detection data at the national level, based on standardized methods, to ensure consistency and comparability within and between countries and to show trends over time. Reporting should focus on new case detection and should include breakdowns by age, sex, type of disease and disability grade, as well as treatment completion rates.

After an in-depth review of available information, the TAG does not consider leprosy to be an eradicable disease. The evidence for an animal reservoir in armadillos, gaps in current understanding of epidemiology, transmission, immunology and the lack of effective tools to reduce incidence, mean that it would not be appropriate or credible to embark on an eradication strategy at this point in time.

The workshops for health service managers and the accompanying training guides, developed for the implementation of the Global Strategy and its Operational Guidelines, are endorsed by the TAG, and their use in strengthening and sustaining capacity in national programmes is strongly recommended.

National Programme Managers should be aware of the clinical problem of HIV/leprosy co-infection. These patients are at risk of severe reactions and may present with Immune Reconstitution Syndrome after starting Highly Active Anti-retroviral Therapy (HAART). The TAG noted that research in this area may improve our understanding of the immune response in leprosy.

Longitudinal monitoring of drug resistance in leprosy is critically important to ensure the continued effectiveness of the leprosy control strategy based on MDT. In this regard, annual reporting of the number of relapses and their verification will be an important activity as part of the national surveillance for drug resistant leprosy.

Future research in leprosy chemotherapy should focus on simplified regimens. Appropriate treatment regimens need to be developed for patients with rifampicin-resistant leprosy and those who cannot tolerate rifampicin.

Further action is needed to improve patients' access to currently available interventions for early detection and management of leprosy neuritis and reactions. The TAG also noted that research is needed for the development of improved tools for leprosy prevention, diagnosis and chemotherapy.

The TAG reiterated the principle that self-care is an important component of disability prevention and rehabilitation initiatives. The TAG recommends that persons affected by leprosy be routinely provided information on self-care such as that recommended in the WHO booklet "*I can do it myself*".

The TAG recognizes that stigma associated with the disease has had a negative impact on all aspects of the Global Strategy for Leprosy Control. Social action is required at all levels to reduce stigma. Further research is required in developing indicators for measuring the degree and impact of stigma and discrimination. The indicators may be useful for the evaluation of interventions to reduce stigma.

***

Dr. Margaret

Holding my arm, she said, "Ymelda, did you ever think that you would be helping me walk around?"

I saw her from across the room
Time unforgiving
Has touched her
As it has touched me!
She still walks in beauty
While holding to humility
And her eyes still shine like the bright blue sea.

"Dr. Margaret, I'm so glad you're still around…"

We hugged
And I cried
My heart filled with memories of the past
When she connected
To her patients
Authentically and humanly;
Alleviating their pain,
Giving love, hope, faith and compassionate understanding
Words vibrant with knowledge and the wisdom of the ages.

"Dr. Margaret, I'm so glad you're still around…"

And after all these years, she still inspires me,
She still moves me

"Dr. Margaret, I am so glad we're still around…"

Ymelda

Dr. Margaret Brand was the "eye doctor" at Carville for many years and recently she and Ymelda Beauchamp were reunited as members of the American Leprosy Mission Board.

Witnessing a World Event in India

by P. K. Gopal, Ph.D.

I am happy to write this article for publication in The STAR about the 17th International Leprosy Congress, held at Hyderabad, India from 30th January to 4th February 2008. This conference takes place every five years in the country which agrees to host it. The ILA (International Leprosy Association), in collaboration with the Government of India, The Nippon Foundation, ILEP(International Federation of Anti-Leprosy Associations), World Health Organization, Novartis, IDEA and ILU(International Leprosy Union) organized the 17th International Leprosy Congress at Hyderabad. Hyderabad is one of India's historic cities with very progressive Information Technology resources. This meeting has traditionally been a scientific congress in which the delegates present papers for the discussion of effective methods for the control of leprosy, future plans on research for improving current medications, seeking a cure for leprosy, and on the social aspects of leprosy.

The social aspects of leprosy have received little attention in the previous Congresses. Since I was a member of the National Organizing Committee for the 17th International Leprosy Congress, along with Mrs. Anwei Law from IDEA international, we proposed to include 30 percent of the Congress Programs on various issues of social aspects in leprosy. This proposal was accepted with the support of ILA President Dr. S. K. Noordeen and other members.

The Sasakawa Memorial Health Foundation of Japan provided sponsorship to the Congress for 100 persons from India who have been affected by leprosy. Among them, 16 persons presented scientific papers at the Congress. From other countries, 50 persons affected by leprosy and their supporters attended the Congress and presented papers. This total of 150 leprosy affected persons attending the Congress, represented more than 10 per cent of the total Congress delegates. On the last day, a trip was arranged for the IDEA participants who had come from abroad to visit one of the leprosy villages near Hyderabad city.

A Pre-Congress Workshop on “Stigma, Identity and Human Rights” was held for 2 days in which persons affected by leprosy from 17 countries participated. On 31st January, Mr.Yohei Sasakawa met all of the persons affected by leprosy who were attending the Congress. All were happy to meet Mr. Sasakawa and took photos with him. Dr. Noerine Kaleeba, a vibrant activist in the HIV field, shared her experience with stigma, discrimination, and human rights in the Keynote speech to the Congress.

The 17th International Leprosy Congress was an opportunity for leprosy-affected participants from 24 countries to experience the presentation of scientific papers and equally participating with other skilled workers in the leprosy field.

All the participants of IDEA and the National Forum who represented people in India affected by leprosy in India stayed in four hotels and, unlike at other occasions, were well accepted by the hotel's management. On behalf of those affected by leprosy I would like to thank ILA, ILEP, IDEA International, The Nippon Foundation and the Sasakawa Memorial Health Foundation for helping us for achieving this success. This is not an end but a beginning.

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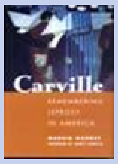
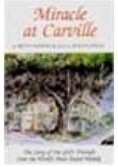
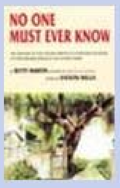
Carville: Remembering Leprosy in America		*Dr. Marcia Gaudet* ***$28.00***
Miracle at Carville		*Betty Martin* ***$20.00***
No One Must Ever Know		*Betty Martin* ***$18.00***
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"Reunion at documentary premier---L to R, J.R. Ramirez, Erika Ramirez, James Carville, Magdalena Ramirez and José Ramirez, Jr."

A Toast to My Brothers and Sisters

by Jose´ Ramirez, Jr.

The National Museum of Health and Medicine, located on the grounds of Walter Reed Hospital in Bethesda, Maryland, was the site for the international premier of the documentary titled “Triumph at Carville.” This site was thousands of miles from the only leprosarium in the continental United States known simply as “Carville,” home for 109 years for many of us affected by a grossly misunderstood disease. However, the existence of thousands who were unceremoniously admitted to the hospital was acknowledged in the documentary for their strength and courage.

As a previous resident of Carville and witness to pain, sadness, laughter, tears, love, loyalty, abandonment, fear, and friendships as solid as petrified wood, I was anxious to see the outcome of the film conceived by John Wilhelm and Sally Squires. I also wanted to share this experience with my wife, Magdalena, and two children, Jose´ Roberto (J.R.) and Erika.

The documentary was seen by hundreds at the museum on March 27, 2008, and by millions on PBS the next evening. My emotions rose rapidly as the Ramirez family entered the museum and the Carville family emerged – James Carville, Dr. Robert Hastings, sisters from the Daughters of Charity, Dr. Wayne Meyers, Mike Wood, the members of the Harmon and Landry families, Dr. James Krahenbuhl, Dr. David Scollard, Marcia Gaudet, Dr. C. Everett Koop, and one of my heroes, Dr. John Trautman. The walk into the museum also resurrected my memories of the challenges faced by my parents, six brothers, and six sisters when I was first diagnosed with Hansen's disease in Laredo, Texas 40 years previously.

The emotions from my family included: J.R.: "Among the statues and monuments of our nation's capital, what better place to showcase a community of history and miracles; a place where Dad's pain and struggles turned into hope, healing and a fulfillment of his American dream," Erika- "It was very uplifting to see the glimmer in Dad's eyes as we celebrated the documentary about a place very dear to his heart," and Magdalena – expressed her sentiments in tears.

"Triumph at Carville" definitely kept my emotions at a high level as the history of the hospital – good, bad, and indifferent – came into focus. My memories of living in such a unique community with two faces were awakened – one as ugly, scarred, labeled negatively and feared, and the other as beautiful, serene, comforting, and of everlasting bonds. The film had too many pictures of persons with disfigurements that can occur when there is little or no treatment. However, it also projected the special beauty of Carville's "Jewel" by highlighting the manner in which many of my brothers and sisters were able to overcome being handcuffed by stigma and eventually triumphed in life. In my opinion, this triumph can best be explained by imagining the analogy of being called out on a third strike (always based on the judgment of an umpire – society). This would be followed by doing the impossible….reversing the third strike by refusing to be labeled, refusing to be separated from society, refusing to be cast as the living dead.

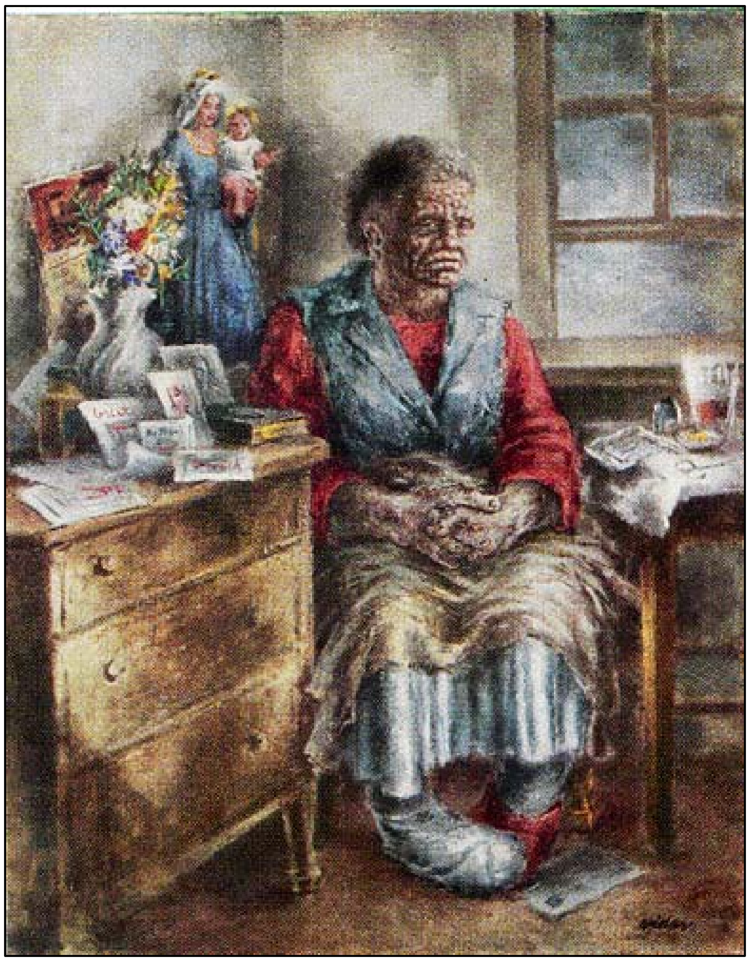
For me, the evening ended with many hugs and tears, and a toast at the reception to the millions throughout the world who are now in heaven, and the millions who continue to face 30 centuries of myths and stigma.

The documentary is a landmark in education and PBS should consider reshowing the film but with a more aggressive effort to publicize the date and time of showing. The premier of such an important film should not be relegated to a one-time showing at 10 pm on a Friday evening. For those who do not wish to wait on PBS, "Triumph at Carville" can be purchased for $24.99 from www.pbs.org and linked to "shop." ***

Correspondant National David Rabius presents The Star Editor Abel Aparicio with a Carville Star team shirt. This picture was taken during the February 2008 visit to Carville.

MOTHERS' DAY Restored

When the 40/8 visited the National Hansen's Disease Museum in February 2008, they gifted the museum with the funding necessary to restore a treasured painting from our collections: Mothers' Day. The oil painting is one of two owned by the museum that dates back to Abbott Laboratories triumphant tour of the hospital in 1947. The two artists involved, Frede Vidar and Howard Baer, were both veterans of WWII who served their country as combat artists. During their two week assignment at the Carville hospital in the summer of 1947 they sketched the leprosarium from fence to fence with the patients' full cooperation.



MOTHERS' DAY. Frede Vidar, artist. Oil on canvas, 1947. 26 x 32". *Commissioned by Abbott Laboratories, with the permission of patients, U. S. Public Heath Service Hospital (National Leprosarium) Carville, Louisiana. National Hansen's Disease Museum, Permanent Collection.*

According to Stanley Stein, "They put in a couple of weeks here, sketching, and popping up anywhere and everywhere to catch the patients under treatment, at work and at play. The artists admitted that they were quite unprepared for the energetic life led by the patients here. The completed Baer-Vidar collection of some 70 pictures was done in oil, pastel, ink and watercolor, and represented scenes of this hospital and various phases of local patient life."

The result was a sweeping pictorial survey of the "Miracle at Carville" reproduced in gorgeous colors and energetic lines, depicting life at Carville after sulphone therapy brought hope of recovery. Abbott Labs sponsored the documentation to advertise the amazing effects of the drugs they were manufacturing.

Most paintings illustrate how the new drug treatment gave patients renewed vitality, Mothers' Day, however, pictures a despondent woman who was apparently diagnosed with Hansen's disease years before there was the hope of a successful treatment. Abbott Lab published the following caption for Mothers' Day in their magazine "What's New":

> MOTHER'S DAY—She has not been forgotten. Snapshots and greeting cards from her grandchildren brighten Mother's Day for this patient. Correspondence is restricted only by the rule that all outgoing mail must be sterilized. Very recently the community acquired its own branch post office, known as Point Clair, with a patient handling postmaster duties. Patients with the amount of disfigurement shown here, always in the minority at Carville, are becoming an even rarer sight in the sulfone era.

The story of how the museum acquired "Mothers' Day" is almost as interesting as its origins.

In 2002, Richard Riseberg, an attorney for the National Institute of Health in Washington, D.C., was in the process of retiring after 35 years of service. "Mother's Day" had been hanging in his office for most of that time.

In 1975, during a regular noon card game in the attic of the NIH with co-workers, he found the painting--hanging face to the wall. Intrigued, Riseberg asked the NIH director, a fellow card player, if he could hang it in his office. The director readily agreed and there it remained until Mr. Riseberg felt compelled to find its true home 35 years later.

On the back of the painting the artist, Frede Vidar, wrote "Carville, 1947." With a little Internet research Richard Riseberg located the museum in Carville. He offered to ship the painting home in a custom-made crate--as he was convinced that it belonged here. Unsure of what to expect until the crate arrived we were thrilled to realize that the museum had been "gifted" with one of the original Abbott Lab paintings.

The museum has only one other painting of that series. "Bundling the Star" hangs in the main exhibit room. It was restored with the generosity of 40/8'ers two years ago. The location of the 68 remaining "Abbott" paintings remains a mystery. Reproductions of many of the original paintings with legends written by Don Fitzsimmons for WHAT'S NEW (and reprinted by The STAR in December 1948) are part of the National Hansen's Disease Museum's permanent collection.

Over the last 60 years, Mothers' Day had become dull and muted by dirt. The painting needed a good cleaning. Moreover, there was a small hole through the canvas and no backing—meaning the fragile canvas could be exposed to further damage. With funding in place, the museum contact New Orleans Art, Inc. After examining the painting, Conservator-In-Charge, Blake Vonder Haar, told the museum that the cleaning and repair would be standard in nature.

First, the painting was de-framed by laying the painting, with the back up, upon a flat stable surface covered with a soft cushioning material, and carefully vacuumed. Great care is needed during the vacuuming to avoid the flaking or cracking of the paint.

Foxing, a form of mildew, was easily removed with an anti-mildew agent, containing Sodium Hypochloride. A clean cotton wool ball is sprayed with or dipped in this solution. The affected area is then lightly rubbed with the anti-mildew agent and then wiped with clean water on a sponge until all traces of the anti-mildew agent are removed.

In-depth cleaning was done by removing the varnish. Oil paintings are normally coated with a layer of varnish applied for the protection of the painting, so that dirt and grime don't directly attach to and enter into the paint. The varnish layer is removed with a pad of cotton wool dipped in methylated spirits. To prevent the methylated spirits from working too deep into the paint, a second pad of cotton wool, this one dipped in turpentine is at the ready to arrest the workings of the methylated spirits.

Tears and holes in the canvas were repaired by flattening the existing canvas, applying a new piece of canvas to the back and touching up the paint. Once the hole was repaired with canvas, the painting was restored from the front. The hole was filled with ground, which can be made by dissolving some fish glue or gelatin in warm water and then adding chalk to thicken the ground to a putty-like substance. Once the conservator was satisfied with the repair, the restoration was finished by revarnishing and reframing the painting.

Once again, "Mothers' Day" is on exhibit in the museum. She is a moving subject who illustrates the pain and isolation felt by many who suffered from the stigma associated with Hansen's disease.

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"Triumph at Carville"….A Voyageur's Perspective.

By Mike Wood, Forty and Eight Carville Star Directeur

On 27 March 2008 I was invited to attend the International Premier of the film "Triumph at Carville" as a representative of the Forty and Eight Carville Star Program. It was held at the National Museum of Health and Science in Washington, DC. This is a film documentary by award winning producer and director John Wilhelm and writer Sally Squires to be aired the following evening on PBS television stations all across the United States. The film was a labor of ten years in the making and it introduces you to the history, medical achievements and life at Carville from its' inception to the present time.

As my wife Sandy and I arrived, I was not sure that I would know anyone attending and felt a little uncomfortable. But as we came into the reception area, I was greeted by a friend, managing editor of The Star, José Ramirez Jr. and his wife, who introduced us to their lovely children. I immediately felt at ease. We were treated to delicious Cajun hors d' oeuvres and wine. I was then taken around and introduced as the Forty and Eight Carville Star Directeur to many people at the reception, including former Surgeon General Dr. C. Everett Koop, James Carville, Past Carville Director Dr. John Trautman and those angels of mercy, the sisters from the Daughters of Charity. As my wife and I were enjoying the food and occasion, I happened to see another friend, Dr. James Krahenbuhl, the Director of the NHDP Center. Dr. Krahenbuhl introduced us to his wife and again we felt very comfortable, and welcomed. The reception was a variety of conversation, new greetings and apprehension of the upcoming film.

José directed Sandy and I to an area in the museum where there is an exhibit set up with artifacts from the Carville Museum. This display was coordinated with Carville Museum Curator Elizabeth Schexnyder who supplied the materials that were on display. In the glass display windows among the medical equipment, pictures, and written material is a gold chapeau….it is the chapeau of Carville Star Directeur Passe Fred Fishel, who served the Carville Star program for many years. It was so good to see the Forty and Eight get recognition with this display. This display will remain there as an exhibit for a year for all to see.

The time had arrived to enter the theater for the screening. As Sandy and I were seated, I noticed a kinship amongst the people in there. The medical community, the former residents, the volunteer staff, writers, NHDP representatives, professionals, and the entire group. It was the atmosphere of a family reunion, or not unlike a gathering of veterans that had all strived for the same goal in a joint effort. I was very moved by this show of genuine affection. Before the film started we were addressed by Dr. C. Everett Koop, John Wilhelm and James Carville. The moment had come that we had all waited for and as the film progressed you could hear the sounds of amazement, sadness and laughter in the audience. I am not a film critic, but with my association with the Carville Star Program, I must tell you that this is a very powerful film. One thing that impressed me was life amongst residents at Carville. We all know the struggles they faced, but in this film you get to see and hear from the residents about the good side of their lives. The Mardi Gras celebrations, Christmas Parties, picnics, sports gatherings, and social life in general. You realize that behind those high fences were men, women and children, not so much different from ourselves, who lived as full a life as possible. It dispels many myths that the public has had about Hansen's disease being the horrible scourge that is linked with biblical leprosy.

After the film was over we returned to the reception area, where we were treated to a dessert and champagne gathering. It was here that I saw the handshakes, hugs, kisses, and a few tears. I witnessed the true emotion within this group of people that I am glad to have met. Numerous toasts were made befitting the occasion including those made by John Wilhelm, José Ramirez Jr. Dr. James Krahenhuhl, Dr. John Trautman, Sister Dorothy Bachlot, Sister Rose Anthony and Sister Francis Louviere from the Daughters of Charity mother house, and Stephen Smith, Senior Advisor from HRSA, the agency that oversees the NHDP. As the evening wound down I felt as if I had learned so much more about life at Carville and had a whole new perspective on it. I am so happy to have the privilege to be a part of the many people working for the good of Carville and the NHDP. Sandy and I said our goodbyes and thanked everyone for allowing us to be there and share that evening.

On the drive back to the hotel it reoccurred to me how I was introduced when we arrived…..as The Forty and Eight Carville Star Directeur. I did not realize at that time just what that introduction meant, but after that evening I was never more proud and humble to be associated with the Carville Star Program, and to be a representative of The Forty and Eight.

FACTS ABOUT HANSEN'S DISEASE

What is HD?

Hansen's disease, erroneously associated with biblical leprosy, 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 Amauer 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 undue difficulty and counteract most of the fears generated by the folklore surrounding this disease.

HD is essentially a disease of the peripheral nerves, but it also affects the skin and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, muscles, bones and 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 1994 the World Health Organization estimated that there were 2.4 million cases of HD worldwide with 1.7 million cases registered on treatment. The estimates for 1985 were 10 - 12 million and 5.4 million respectively. According to these estimates, in 1994, 70% of those who should be on treatment are now being treated. In 1992 there were 690,000 new cases reported and in 1993, 591,000 cases. There are also an estimated 2 - 3 million cases who have completed treatment but who still have residual disabilities who are not included in the above 1994 totals. The largest numbers of Hansen's disease patients continue to be in Southeast Asia and Central Africa with smaller numbers in South and Central America. The largest number of patients in the Western Hemisphere are in Brazil.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began and still living. The number of cases with active disease and requiring drug treatment is approximately 600. There are 200 - 250 new cases reported to the registry annually with about 175 of these being new cases diagnosed for the first time. The largest number of cases in the US are in California, Texas, Hawaii, Louisiana, Florida New York, and Puerto Rico. There are still approximately 23 cases at the Gillis W Long Center at Carville, LA. Most patients in the US are treated under US Public Health Service grants at clinics in major cities or by private physicians.

(See listing of clinics.)

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 90% 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 the rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Usually rifampin and sometimes clofazimine or ethionamide are given in addition to dapsone. Treatment rapidly renders the disease noncommunicable by killing nearly all the bacilli and these dead bacilli are then cleared from the body within a variable number of years.

"The editor is working on updating the information on this page, and it should be corrected by the next issue. We are sorry for any inconvenience"

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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 legionnaires 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.