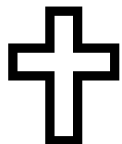
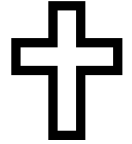




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The Star stands firm in its opposition to the use of the term "leprosy." We shall never abandon our campaign to secure general acceptance of "Hansen's disease." Nevertheless, the word "Leprosy" does appear in **The Star** under circumstances which 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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EMANUEL FARIA: MAKING A LIFE FROM ‘SECOND BEST’

BY
Martha Corson

“Being a Hansen’s Disease patient was not the end of the world. It was a hard time in those (early) days but, Stanley (Stein) taught us that, after all, we could make something of our lives in spite of illness. There is always a second best.”

Emanuel Faria, Editor, The STAR

Excerpt from The texture of our souls; Reprinted with permission from IDEA

When Emanuel Faria arrived at the National Hansen’s Disease Center at Carville, LA, in late 1968 he landed in the infirmary as all new-to-Carville patients did. It was there I met him.

Louis Boudreaux, who was then Chairman of **The STAR**’s Editorial Board, had been told of an unusual new patient by one of the Sisters of Charity. (Note: The Sisters of Charity worked as nurses at the hospital.) Louis promptly dispatched me to meet and greet this new individual.

Emanuel Faria looked drained and exhausted, resting back against pillows on his Infirmary bed. He opened his eyes when my shoes clicking across his room, announced me. Barefoot and clad in blue pajamas he lay on top of the bed. He took one look, I smiled hopefully, and his eyelids fell shut again while an expression of immense suffering crossed his face

His expression was entirely readable: Now I will have to talk with still another person!

Obviously he had already been maxed out on visits by doctors, nurses, chaplains and social workers as well as his curious fellow patients

Also, for the second time in Emanuel’s life, his entire known world and every single person in it had all been swept away. Small wonder he looked so drained.

His initial silence allowed me time to compose myself for he certainly looked like no other I had ever seen.

He appeared to be about 40 with the face of an archangel: clear white skin, high brow, deep-set eyes and thick dark brown hair that tumbled over his forehead. However, as new as I, too, was to Carville I could see that this man had been battling the disease for decades.

His eyes suddenly flew open. Belatedly he remembered his manners and asked me if I would please excuse him momentarily. I noted “British accent” on my notepad and retreated into the hall. Emanuel summoned one of the Sisters and, upon being invited to re-enter, I found him now lying properly covered beneath the bed sheet.

Quickly I got down to business. I explained that I was a professional writer, hired to assist **The STAR** staff, and had been at Carville only briefly myself. I was 32, recently divorced and childless. **The STAR** would like to know more about Emanuel and his life, hopefully for publication, I added. For the first time Emanuel looked genuinely interested. “I have read **The STAR** for years,” he said. A brief pause, then he made a quick decision. “Yes, I will write my story.”

I commented: “I understand you’re from South America.”

“Yes, Guyana,” he replied.

Reluctantly I admitted that I had no idea where that was.

His eyes closed again; the look of acute suffering returned. *Another ignorant American to contend with!* “It used to be called British Guiana,” he informed me wearily. “English is the official language. The country gained its independence from Britain in 1966 and then became Guyana.”

Suddenly I caught a break because I actually knew a little about British Guiana, having written a school paper on it once. “You mine bauxite--like my home state of Arkansas,” I recalled. “Also, diamond and gold deep in the jungle. But the country’s main crops are sugar cane, rice and rum.”

With that Emanuel opened his eyes and began to truly talk to me. He stated that Emanuel Faria was his actual name and what had brought him here, thanks to arrangements made by Carville’s dermatologist, Dr. Herbert Gass, was the need for corrective surgery on his hands. Emanuel added that he’d been an HD patient for many years and had lived in three different leprosaria--the last one close to Guyana’s capital of Georgetown.

When I returned to **The STAR** I told Louis Boudreaux that Emanuel was indeed interesting, that he *might* write something for us but I had no idea of what to expect.

While I waited for Emanuel to produce a story, others in the hospital were becoming aware of him. One of them was my close friend, Tanya Thomassie, then Medical Illustrator of the Training Branch. She visited Emanuel, too, and we compared admiring notes in the Carville Staff Room where I took all my lunches and coffee breaks.

“Hey, ladies, I see that guy every day,” a male therapist across the table suddenly cut in, “and he can be a handful!”

“That sweet man?” Tanya and I exclaimed in unison (and mutual disbelief.)

“More there than meets the eye,” said the therapist who tended to speak in clichés.

About a week later Emanuel rolled into **The STAR**. He sat in a wheelchair since his feet were currently being evaluated. He’d also learned just what bad shape his eyes were in but Carville’s ophthalmologist, Dr. Margaret Brand, thought Emanuel’s sight could be saved. What a relief! Emanuel added, since blindness was the ultimate long-term disability that all HD patients fear most.

Still and all, he looked like a changed man from the forlorn and depressed guy I’d originally met. Now his eyes glowed and his face grew animated as he talked.

From the depths of the wheelchair he clumsily extracted a sheaf of papers along with a black U.S. Government ballpoint pen. Then Emanuel read and Louis and I sat spellbound.

He wrote of being a catholic schoolboy in Georgetown, British Guiana, just 12 years old when the ominous pink spots appeared on his thighs. They became immediately noticeable because, in the country’s hot equatorial climate, all boys wore short pants to school.

Emanuel was promptly sent home from school and told not to return. His mother, already quite ill with some unspecified disease (although it was not HD, Emanuel emphasized), looked closely at his spots. Then, having recognized what he’d contracted, she closed her eyes in despair. “It would be better for you if you would die,” she told the frightened child.

While his mother still lived Emanuel stayed home but upon her death his father and Emanuel’s siblings took him to a leprosarium and left him there. When Louis asked anxiously if they’d written or kept in any kind of contact, Emanuel’s lips curled.

“I neither saw nor heard from any of them again,” he said decisively, pronouncing the subject closed.

The leprosarium’s only empty bed, and the one to which young Emanuel was assigned, lay next to an

elderly man far advanced with the disease. He gasped for air with every breath he drew for in those pre-sulfone days, and without any effective treatment for HD, patients' throats often swelled closed from all the nodules growing inside.

The abandoned child who was Emanuel was unable to eat or sleep for a week. He lay awake on his cot in the dark, listening to the dying patient gasping for breath, and saw semblance of his own future dying with the old man.

"...and so," Emanuel concluded, "...that is how I came to Mahaica Hospital"

A photo of Mahaica taken by an American nurse and published in *The STAR* (July-August 1970) showed "a hospital on stilts." It consisted of five box-like buildings, each taller than the last, strung together and erected atop high pilings. Obviously flooding from the ocean or the country's numerous rivers remained a constant danger.

Quick descriptions of life there from varied sources: "I visited Mahaica, the government hospital, several times," a Protestant missionary told me recently. "It was awfully bad. You could smell the place long before you saw it."

"Mahaica Hospital is on the beach but it isn't a pretty beach," his wife added. "Its color is always brown because the muddy Amazon River empties into the ocean not far away. You can clearly see the demarcation line from an airplane. There's beautiful blue Caribbean ocean for miles until suddenly, this deep brown water starts pouring into it."

From a newsletter by the Catholic Sisters of Mercy of the Dallas Regional Community: "The Sisters also take nourishment into the hills of Guyana to the people of Mahaica Hospital. They have suffered from the effects of Hansen's disease, both physical and social, for decades."

From Guyana 2000 Expedition's website: "Then it was time for us to move on to the Mahaica Leprosy Hospital just outside Georgetown. Many of the

patients have been there for over 50 years... Materially the people have so little and yet their spirits seem so resilient."

Despite Emanuel's inauspicious beginnings at Mahaica, there were still the hills and the nearby beach to explore and the intelligent young boy scoured both. The Medical Superintendent of the hospital at that time, a Dr. Rose, was "a brilliant black man," according to Emanuel. Dr. Rose had been educated in Britain and he took Emanuel as his special charge. So did the Sisters of Mercy who served the patients of the leprosarium.

Louis asked Emanuel what he had done during all of those years.

"I withered," Emanuel said quite matter-of-factly. "I languished."

Had he married? asked the happily married Louis.

No. Patients were never allowed to marry. "I worked as an orderly. I read everything I could find. I visited with Dr. Rose and the Sisters. Or I walked along the beach," Emanuel added.

Because British Guiana lay next to French Guiana with its infamous convict labor camps (which were actually death camps, Emanuel emphasized) many convicts hatched desperate escape attempts by sea. The more successful, carried by the tides, sometimes wound up on the beach near Mahaica Hospital.

"The patients would see them and set up a cry of 'Frenchmen on the beach, Frenchmen on the beach!'" Emanuel related. "That brought the doctor and nurses running. Dr. Rose never sent the convicts back to French Guiana. We could see their deplorable condition. They'd been starved, beaten, eaten alive by all the insects in the jungle. Sometimes they looked so bad they frightened us. And sometimes--" Emanuel recalled with a small laugh, "--we frightened them!"

(Note: In 1956 France bowed to international pressure and dismantled these prison camps.)

One bright spot in Emanuel's grim day-to-day

existence was the arrival of **The STAR** six times a year. Dr. Rose always brought it to him to read and it was there that the South American patients first learned of the ‘miracle at Carville’, which the sulfone drugs had wrought. With their own disease worsening rapidly and knowing what lay ahead, they begged Dr. Rose to import some of the new wonder drugs.

“Bah!” the doctor exclaimed to Emanuel. “This is just another flash in the pan ‘cure’ like so many others we’ve both seen. Besides, no studies on sulfone drugs’ use in leprosy have appeared in the medical journals.” Dr. Rose believed in taking a cautious wait-and-see approach.

But with each new issue of **The STAR** carrying exciting medical news of patients cured and even discharged from Carville, the South American patients clamored all the more. Finally Dr. Rose capitulated and spent some of his precious resources--precious because he had so few funds to work with -- and Mahaica Hospital also entered the sulfone age. Emanuel was one of the first patients to receive the drugs and one of the first to become bacteriologically negative.

Even the skeptical Dr. Rose was soon won over as he saw his long-time patients’ downgrading conditions stabilized at first then reversed. “These results are truly astounding!” He said to Emanuel.

At last Emanuel had regained his health. He might have reclaimed his freedom, too, but where was he to go? What could he do to support himself?” The miracle drugs could not restore his hands and feet. And his eyes, so damaged for so long, continued to worsen relentlessly. And then the opportunity arose for Emanuel to come to Carville, thanks to Dr. Gass. That concluded both his story and the interview with us.

While I sensed certain omissions in the public story (i.e. like what happened to the other two leprosaria where Emanuel claimed to have lived?), Louis pronounced himself satisfied. **The STAR** would print Emanuel’s story and its author appeared overjoyed. Later in the Staff Room I spoke of Emanuel with Dr.

Gass and commented on his natural flair for words. “He’s quite a remarkably intelligent fellow,” Dr. Gass said warmly. “Completely self-educated. He’d be an asset at **The STAR** if you could help to get him hired, and I can’t tell you what it would do for him psychologically, I mean. Right now he thinks his life is over, that he’s finished.” Dr. Gass paused. “Did he tell you how he happened to come to Carville?”

After I’d recounted the surface story, Dr. Gass shook his head. “When I arrived at Mahaica Hospital I was met by Sister Carmen, An American nun who works there,” he related. “She said, ‘God has sent you in answer to my prayers!’ Which I certainly found startling. Then she told me she needed to get Emanuel out of the hospital because he was in deadly danger there.”

“What?” I said incredulously.

“Get him to tell you the story,” Dr. Gass urged.

“Not if he’s a danger to himself or others!” I blurted. Dr. Gass dismissed my concerns. “Oh no! This was a political situation

How the devil did a patient in a leprosarium get mixed up in a political situation? I wondered. But in those dark days of the Vietnam War, and with the American sorely divided on its worth or lack of it, all sorts of things had suddenly become political.”

Meanwhile, lacking a proofreader, I carried several typeset proofs to Emanuel’s hospital room. I showed him the most common proofreading symbols and left them with him. He returned them to me within the hour, all spelling and punctuation errors neatly circled.

This was enough for me. To Louis and the other members of the Editorial Board I made a pitch for Emanuel’s becoming a regular STAR staffer. We had recently lost Ernest D., off to pursue higher education at LSU, so the other desk in my office was empty. After a day or two, Louis returned with a less than enthusiastic, “Well...okay. He can start next month.”

I then made a crucial error of running to tell Emanuel the good news. He grew so elated at the prospect of

working at **The STAR** that he even quit giving his therapist a hard time!

Just a day after Louis had agreed that Emanuel could be hired, Tanya came smiling into the Staff Room and announced that she'd also received a go-ahead to hire Emanuel in the Training Branch.

At an age when most men are looking ahead to retirement Emanuel began a brand new career -- one that would last for thirty-six years.

Emanuel quickly established a reputation for being the most industrious member of the staff. Despite his four daily treks back and forth to the Eye Clinic he didn't lose any work time because he always arrived early and he stayed late.

With his new eyeglasses, a nice desk all his own and a paid job, Emanuel was like a man reborn. We noticed that he began to gain weight on his new American diet. Now, for breakfast, he could have all the 'porridge' (oatmeal) that he wanted. "I am very fond of porridge," he told me solemnly. He also devoured, in a different sense, the medical journals that arrived almost daily at **The STAR (Lepra, The International Journal of Leprosy, The Indian Leprosy Journal, The Journal of Rehabilitation in Asia, etc.)** as well as any newspaper articles on "leprosy" that our clipping service furnished. Daily he called things to my attention that I might otherwise have missed, there was always so much material to read and keep abreast of.

If both of us thought an article published in some other journal was an especially pertinent one then Emanuel condensed it for our publication. He also showed a particular knack for fitting written material into available space. If I said, "can you cut it by four lines?" He could do exactly that.

Emanuel also mastered the two phone--one to the outside, one exclusively for "**The STAR**, Emanuel speaking," he always said pleasantly. Certainly his catching every-other-call proved helpful although we soon played the "Your turn!" game when we were both busy.

Emanuel's presence also freed up Louis Boudreaux up from any further editorial concerns. Now Louis could concentrate exclusively on building **The STAR's** relationship with our principal sponsor, The National **Forty and Eight**, a veterans' organization.

Meanwhile I did what we'd discovered I could do best: schmooze with the staff. Since I went to the staff room three times daily for lunch and coffee breaks it was easy enough for me to cover the doings in Carville's various departments.

Emanuel and I interviewed all visiting leprologists from other countries and solicited articles for **The STAR** from their parts of the world. Early on we were both concerned with making **The STAR** more of an international magazine and launched a version in Spanish, La ESTRELLA. I also typed letters by the dozens to foreign countries, picking names Emanuel chose from various leprosy journals. Once a damaged and strange looking packet of material and photographs arrived bearing the postmarks of fully a dozen different nations. I immediately handed the envelope to Emanuel since he collected stamps while I pursued its contents.

"It's from Russia!" we exclaimed in unison, then disbelief: "**Russia**".

In those days of the relentless "Iron Curtain," communications with the Soviet Union were severely limited. Censors from both countries, theirs and ours, had already scrutinized the article inside. Soon the entire STAR Staff, even the Chinese and Mexican patients who worked in the Pressroom and were usually indifferent to the magazine's contents, gathered around us while Emanuel read the article aloud. Written in good English, a Russian doctor in a leprosarium there thanked us for publishing **The STAR** which he'd found "very helpful." Might we consider the enclosed article for publication? While it was short on specifics--like how many patients with Hansen's disease there were in Russia or where the most cases in his country were concentrated -- we were still delighted and rushed it into print. Our 'Russian coup' even brought Dr. Kirchheimer around

and soon we were talking both with him and his associate, Dr. K. Prabhakaran. Through this connection with the Laboratory Research Branch we received masses of more information to plow through, some of it highly provocative like the attempts to transmit *M. Leprae* to rattlesnakes by a California researcher.

One of mine and Emanuel's early projects, celebrating the hospital's 75 years of existence, grew into a historical series. Emanuel had read all the materials available both at **The STAR** and in the scrupulous records kept by Carville's Sisters of Charity. He presented me with a long list of facts, quotes and yellowed newspaper articles. I tied them to the thoughts and emotions I believed the first seven HD patients, sent upriver from New Orleans to Carville on a coal barge, must have experienced at their exile. Emanuel, who declined to write anything "emotional," verified the patients' feeling at being declared outcasts from civilization.

To our amazement The Canadian Medical Journal reprinted the story we called "Out of Darkness", because the coal barge had left at nightfall so its 'cargo' could not be detected. The Canadian editor even demanded our names so he could give us proper by-lines that we had not given to ourselves. This series of historical articles ran for the next year with several articles reprinted widely. But Emanuel never overcame his aversion to anything "emotional," not even when he told me how he'd felt with the realization that sulfone drugs were curing him of "the ancient malady"-or, sometimes, he referred to HD as "a cruel affliction." These were his favorites terms for the disease since he disliked "leprosy" but didn't think the mild-sounding "Hansen's disease" truly conveyed its mysterious and sinister aspects.

Meanwhile the available typewriter on Emanuel's desk kept luring him like a siren's song. He'd never had "such a wonderful piece of equipment before" (Emanuel's term for an elderly manual Underwood.) Gradually he taught himself to type hunt-and-peck style, using a yellow pencil that he held eraser-side down in his right hand. Peck, peck, peck... "Oh,

mon!" he'd mutter, telling me he'd just made a mistake. Peck, peck... "Oh, mon!" While this was maddening to listen to, he gradually became so proficient that I no longer had to type up his writings.

Only Emanuel's occasional use of the word 'mon' for 'man' betrayed his Caribbean roots. Indeed in his early heady days at **The STAR** Emanuel was quick to renounce anything from his past life in Guyana. He particularly disliked both of the country's two leading political rivals.

Once Emanuel brought in his Guyanese passport. "You want it, you can have it!" He declared dramatically, dropping it on my desk. "Cut it up into a million pieces, I don't care!" I returned his passport to his shirt pocket and admonished him against destroying an important legal document.

But a short time later I feared Emanuel would do exactly that. From Mahaica Hospital in Guyana **The STAR** received a particularly nasty piece of hate mail. "You should be warned about your new co-worker, Emanuel Faria," the letter began. "He is a treacherous and deceitful man. . . ." I immediately went into Louis Boudreaux's office and closed the door, a rare occurrence at **The STAR**, but I didn't want others to overhear me when I read him the letter.

Louis and I agreed that we had to tell Emanuel about it but we also knew he'd flip out. This had become our term for those rare instances Emanuel, whose personality was usually pleasant and bland, suddenly went ballistic. This could happen in a nanosecond, we'd learned, and the Poison Pen letter certainly did it. First Emanuel's face went ashen, then its color deepened to crimson fury. Nothing we said could calm him. Even my tearing the letter up and dropping its pieces into the wastebasket didn't make Emanuel feel any better.

"All those years!" he exclaimed suddenly. "Years and years of helping and serving my fellow patients! Do you know what they **did** to me? Because I believed in democracy and they didn't, they dragged me across the courtyard and beat me up! They beat me quite

severely! And when I finally recovered I knew I was finished in Guyana. It was no longer my country because they would try again. They would kill me if they could!”

With that awful story finally revealed we could at last sympathize with Emanuel. Privately I'd already done research on Guyana and realized the country was having one of its periodic political upheavals. The results had been riots, fire and wide scale looting and wreckage. Its diverse population was (and still is) approximately 50% East Indian, 36% black, 7% Amerindian. The remainder, described as “white (primarily British and Portuguese), Chinese and mixed” comprised only 7%. With half the population favoring a Socialist government and the other half one that was Communist, this was not a good time to be white, politically conservative, pro-British and harbor democratic leaning as Emanuel did. It was also no time to be outspoken -- and he always was.

Although safely in the U.S. now he still felt persecuted. Perhaps, given his history, he couldn't help it. Other patients at Carville--those who didn't work at **The STAR**--often found Emanuel “unfriendly,” even hostile. And although Carville's doctors were committed to keeping him in the States, particularly given his contributions to **The STAR**, Emanuel still awoke every morning, fearing he might be deported, sent back to Guyana and to probable death.

But for all of Emanuel's disavowals of Guyana, I noticed that he still read the Guyanese newspapers sent to him by another friendlier patient back in Mahaica. Once he gave such a sharp exclamation of dismay that Louis Boudreaux and I both hurried over to see what was wrong.

“Sir David Rose is dead!” Emanuel said, his voice trembling. “He was killed in London.”

Sir David, he explained, was the son of the Mahaica Hospital superintendent who had been Emanuel's mentor as well as his doctor. “Why, I watched David grow up from the time he was just a little boy,” Emanuel continued. More recently Sir David had

aligned himself with Forbes Burnham's party, becoming the country's first Governor General, the Guyanese equivalent of Vice President.

Although Emanuel feared a political assassination, both British and Guyanese governments eventually concluded that the prominent statesman had simply been at the wrong place at the wrong time (i.e. a construction site where he was killed by a piece of falling debris.) He left a British-born wife, Dr. Patricia Rose, and six young children.

Both Dr. Rose and Sister Carmen Gannon later visited Carville -- the latter several times -- and each had private visits with Emanuel. In the early 1980's Dr. Patricia Rose headed the HD program in Guyana and wrote of that nation's continuing prejudice toward those suffering from leprosy: “It is still feared as an incurable, contagious disease.” This remained the country's attitude almost forty years after the introduction of sulfone drugs.

No wonder Emanuel despaired of Guyana!

But life for him and the rest of us at **The STAR** wasn't always deadly serious. We held frequent birthday parties in the huge Pressroom, with cakes and brightly wrapped presents, and we regularly clustered around the magazine's coffeepot to discuss sports and politics. At these social gatherings Emanuel was usually the last to arrive and the first to leave. Clearly he was a man in a hurry, always anxious to make up for lost time.

During one Christmas season I invited **The STAR** Staff to my apartment in Baton Rouge for dinner. At the last minute I remembered that Emanuel had said he liked rum on festive occasions. So I made an emergency run to the liquor store for Barcardi Dark. While Emanuel drank it he vowed it did not compare to the famous Demerrara rums of Guyana.

One cold winter's day a patient stuck his head in **The STAR** and yelled that it was snowing. Emanuel dropped everything and dashed outside. Behind him, and almost trampling each other in their eagerness to

see the snow, came Hawaiian, American Samoan and South American patients.

Although snow was rare in South Louisiana, it wasn't unheard of. But almost a third of the adult patients working at **The STAR** had never seen it before. Emanuel pronounced it "beautiful ... wonderful!" But when I asked him to record his first impressions of snow for a short STAR article, he balked. "I can't do that," he finally admitted. "I can't write from scratch."

He could edit, cut and condense successfully but he was simply not creative.

People often commented on Emanuel's "seriousness" but he did have a sense of humor. While I didn't see it often, he made remarks both clever and sly. Eventually we shared a couple of running jokes, the longest one involving the thick Oleander bushes at Carville.

Another lighter incident, later recalled as 'Emanuel and the feminine emergency' involved Moira M., a lovely young patient in her mid-20's from South Texas. Moira, who worked as Louis's secretary, could usually coax copies out of our primitive and balky liquid copying machine.

Louis, who couldn't see the cantankerous thing, gloried in it since it had come to us **free** and this was definitely Louis' preferred price for equipment. Emanuel thought it another marvelous piece of equipment. Moira and I regarded it dubiously since it wasn't a Xerox. Later I asked in the Staff Room if anyone there had used this particular brand of copier.

"I did," said one doctor, "and it's a piece of crap!"

That's exactly what Moira and I began calling the copier, too, after wrestling with its viscous liquids. When Louis ordered us to quit using that term, it became the "POC" instead. After several weeks, which saw one of my skirts stained beyond repair, I

demanded that the contrary thing be removed from my office. I went back to using carbon paper but Moira continued to fool with it.

Then one day she came into work wearing a new spring dress which I admired as she twirled around. Louis and Emanuel interrupted the fashion parade to ask Moira to make some copies for them. "Sure," she said nonchalantly and headed back to the coffee room where the POC had been relocated.

Next came a shriek of purest horror, then the sound of running feet pounded toward my office. "Come quickly!" Emanuel panted, his face crimson. "There's a dire feminine emergency!"

I heard the 'dire feminine emergency' as soon as I hit the hall: Moira's blue language, screamed at the top of her lungs, and she wasn't using any initials, either. Louis, who was nearly as distraught as Emanuel, came tapping his way up the hall with his white cane. "Moira's using words even **I** wouldn't use!" he exclaimed. "I didn't think nice women **knew** such words!"

Before I even reached Moira, I knew the POC had just destroyed her new dress.

The STAR bought its first Xerox machine later that same week.

All in all, Emanuel Faria and I shared an office for almost six years.

Through the pages of numerous old STARS I've tracked him from the very bottom of the magazine's masthead, as a lowly "Staff Writer," to its top: "Editor."

I always admired him for his courage, persistence and hard work on behalf of **The STAR**. Even when I didn't always like him, I still enjoyed talking to him. Emanuel found foreign affairs fascinating and stayed current on news. Certainly I can credit him for inspiring in me an interest in South America that continues to this day.

Once I contemplated setting a novel in Guyana. In the mid-1980's. I began to sell romance novels and little known sittings, preferably in the tropics, were sought by their editors. Mine grew quite enthusiastic about Guyana as a background. Since I was still living in Baton Rouge, I phoned Emanuel with the news.

Two days later we sat down at **The STAR** with his photographs and memories and my notebook and a brand new Fodor's Guide to South America. Emanuel soon had me scribbling a list of Must See places in Georgetown: Its world renowned botanical gardens, St. George's Cathedral said to be the tallest in the world and made entirely of wood, the huge Stabroek market, an imposing cast-iron building with a striking clock tower. And I **must** stay at The Pegasus Hotel! Of course I'd also want to take a side trip to Kaieteur Falls for these were considered among the world's four most impressive water falls.

When I heard both wistfulness and homesickness in his voice, an idea occurred to me. "Emanuel, why don't you go back to Guyana for a visit? I know you've saved your salary and since you're an American citizen now . . ."

"No, I won't ever go back," he replied decisively. "But you must come and visit me again on your return. You can bring me Newspapers and tell me about Guyana today."

Unfortunately that trip never materialized since the State Department soon warned Americans against traveling to Guyana. Street crimes and physical violence had grown common with hooligans even yanking earrings from women's pierced ears.

When I reported that I couldn't go, Emanuel wasn't surprised. Dr. Patricia Rose had recently left Guyana for good, he told me, returning to her native Britain.

After that I rarely saw him. Then we spoke only briefly but we parted as friends. Emanuel grew stout and grey-haired, relying on a walker to get around the hospital, his age revealed at last. The last few times I saw him his hair whitened, he was thinner and he rode about Carville in an electric wheelchair.

One by one other STAR Staffers received medical discharges, retired, resigned because of poor health, moved to Summit Hospital in Baton Rouge or were "gone via natural attrition" which was one of Emanuel's more colorful phrases for death.

With most of **The STAR** staff having departed, publication of the magazine went from regular to sporadic. Finally only Emanuel remained in the office, receiving help from Bill Kikuchi, who drove up often from his home in New Orleans. Emanuel also credited Tanya Thomassie, a government employee still, with helping him to keep him going as well as Dr. K. Prabhakaran, his medical advisor and a regular contributor of original articles to **The STAR**. He also found the National **40 & 8's** continued assistance utterly invaluable.

Through the years of his long, long life Emanuel Faria changed **The STAR** as decisively as either of its previous three editors had. He actively solicited medical articles recalling, no doubt, how **The STAR** had once scooped the medical journals and helped bring sulfone drugs to heal him. Probably he also recalled that article we'd received from Russia for **The STAR** went to numerous faraway places that could not afford expensive medical journals. Gradually the magazine took on more of a medical and international flavor and less of a local one, even as the editor himself became a Carville institution.

When Emanuel's physical health began to fail, he was temporarily moved to the Summit Hospital in Baton Rouge, where he grew increasingly unhappy. He wanted to get back to Carville, to **The STAR** and his work there. Earlier, on the very day he died, Emanuel asked for "one of the doctors." An HD specialist saw him and she assured him he could indeed return "home" soon. Relieved and at peace, he died an hour later.

When I learned he had died the picture that rose in my mind was of a younger Emanuel Faria with a slender frame and thick brown hair. I saw him rocking back in his high top black shoes when he greeted any one of Carville's doctors: "Ah, Professor --" he always began.

Or Emanuel looking up at me with a sly expression, always a prelude to a joke. “Yes something should be done about the most obnoxious person. Why don’t we invite her to **The STAR**? We’ll serve her a nice cup of White Oleander tea.”

“But, Emanuel, that’s a deadly poison!”

“Is it?” he inquired innocently. “I wouldn’t know. There are so many White Oleanders here and all in full bloom.”

Serving someone ‘a nice cup of White Oleander tea’ became one of our running jokes--and one with which we occasionally threatened each other!

So I remember the Emanuel Faria who had been my co-worker and companion -- a unique and fascinating fellow from an exotic faraway land. A man who spoke casually of scarlet macaws, howler monkeys and rivers that ranged in color from brightest Caribbean blue to black-as-night. Again, I heard him describing

tropical rainforests and torrential afternoon rains.

During a life lived almost exclusively within hospital walls and saddled with a disease that still scares the daylight out of people, Emanuel found his way through. He never wasted time lamenting ‘what I might have been but for this disease,’ as I occasionally heard other patients do. Rather, he set about doing what he could to become a useful, contributing member of his insular society. In the process, he left a profound impact of those of us who knew him.

Emanuel definitely got handed a Second Best by life but, overall, he sure made a First Class job of it!

Still, the man who became an American editor could never entirely say goodbye to the land of his birth. And possibly, in his dreams before his death, Emanuel had found himself back at Mahaica Hospital in Guyana. And perhaps, just like those French convicts he used to help rescue from the sea so long ago, he had at last made his own successful escape. ★



(Left to right) Louis Boudreaux, Martha Corson and Emanuel Faria, The STAR Officers 1969.

Photograph Courtesy of American Leprosy Missions

Martha Corson, a professional writer, teaches classes in Creative Writing at Louisiana State University, Baton Rouge, and The University of New Orleans. When she is not in Louisiana, she is at home on Whidbey Island, WA.

★★★★★

AN ERA ENDS AT CARVILLE WITH THE DEATH OF EMANUEL FARIA*

Not unlike Father Damien and Stanley Stein, Emanuel Faria was a man with a mission.

Emanuel began life in Georgetown, Guyana, and learned at an early age that self determination was his best direction.

He came to the United States in hopes of seeking citizenship and a better opportunity for a better way of life in 1968. Mr. Faria was a self-educated man, with a love of history. His most prized possession was the American Flag he received when he became an American Citizen. For all official photographs that appeared in the press, he always requested that his American Flag be included in the photograph. Emanuel stated on one occasion that he has always admired the United States and feels his arrival in the United States is the fulfillment of a life-long dream.

Emanuel became a staff writer and worked his way up the editorial line to become Editor of The STAR magazine. He gave The STAR magazine a future by bringing the publication into the digital age in 2001 through online access. This meant learning to navigate the internet and computer during his 80th decade of life.

He was a member of the ALM board for many years and through his dedication and generosity to those less fortunate than himself, he provided scholarly and monetarily to others. He was dedicated to making this a better world for all.

Emanuel was an intelligent, conscientious, hard working individual who continued to educate himself throughout his life. He rose to the task at hand and today, anyone worldwide can read The STAR free online, and it can be published from any location, not just behind the gates of Carville.

Mr. Faria was a great crusader and a man whose life was both an example and inspiration to others. His friends will miss him and are grateful for the time shared with such a fine fellow. For his courage, contributions, and his refusal to give up, we thank him.

★

*Forty and Eighter
June, 2004

USA

The Last Farewell

The shining STAR that radiated so much hope and support to the people afflicted with Hansen's Disease has lost some of its lustre. Like all stars the strength, the energy within will eventually fade into the darkness of the night

Because of his suffering and abandonment, he fought to educate the world of "The Curse" to bring dignity to other unfortunate human beings who suffered the agonies of mental and physical pain, the shame and the heartaches.

Through his efforts and all the editors before him we are now being treated with understanding and compassion and at long last, being accepted in the mainstream of life.

*We shall never forget him
May he rest in peace*

★

★

Messages from IDEA members around the world for Emanuel Faria

Japan

We were surprised and saddened to hear of the death of our dear and respected friend, Mr. Emanuel Faria, the editor of **The STAR** and our esteemed friend. I offer our most sincere condolences.

With a special emotion and admiration, I recall a meeting with him in June 2002 when we visited the GWL Hansen's Disease Center at Carville. He was sitting behind the editor's desk of **The STAR**, dignified and impressive, and told me about **The STAR** and its role in the long history of Carville. I shall never forget his intense and piercing eyes. It was a moment that has never left my memory and I will forever cherish it. Without realizing he was much senior to me, I said to him let us continue our effort. He responded to me with a big nod and words of encouragement.

His departure, no doubt, will be felt especially with regards to the future of **The STAR**, but Emanuel Faria will always be in our memory with his undying fighting spirit against the stigma associated with Hansen's disease.

May he rest in peace.

Yasuji and Noriko Hirasawa, Tokyo, Japan



Korea



Mr. Emanuel Jesus Faria will be forever remembered in our hearts, and has been a great leader in standing tall to promote the rights and interest of persons affected by HD and to correctly let people learn about HD itself through **The STAR**. We all know how much he meant to those affected by HD in the world. He completely finished his given talent from God and now he rests in peace and love with God who is in heaven.

With all my warmest wishes

Hong Sun Woo



China

We are exceedingly grieved to know Mr. Faria passed away today. It is not only a great loss to **The STAR** and Carville, but a great loss to all people who work in the leprosy field. With great contribution of Mr. Faria, **The STAR** has become a very important periodical from which we have learned a lot and been inspired. We will try to carry out his spirit and try our best to work for a world without stigma and discrimination, and a world with understanding and peace.

Please convey our deepest condolences

**Dr. Yang Li He on the behalf of
HANDA/IDEAChina
with great grief**



India

The leprosy world has lost the great man, Emanuel Faria. **IDEA** will really miss him. His contribution through running **The STAR** is something invaluable. I knew him personally and met him in his office at Carville. In fact he was an example to me as far as execution of work, even at an old age. He was tireless in carrying out the activities. I have admired his ability to carry on **The STAR** all those years.

We in India pray for His soul to Rest in Peace.

Dr. Gopal, on behalf of people affected by leprosy



New York, USA

I was so sad to hear of Emanuel's passing In his passing goes a legacy of a man who worked hard to keep **The STAR** alive. I remember when I went to Carville and first met and photographed Emanuel. It occurred to me as I was taking his picture, that all editors lean back in their chair in a certain manner and that he had the same posturing of Ben Bradley, once editor and chief of the Washington Post and New York Times, whom I had photographed for Washingtonian Magazine.

Yes, Emanuel was once affected by Hansen's Disease but at that moment and in the many moments I spent with Emanuel he was first and foremost the head editor of a paper! Completely engrossed in his subject, opinionated in his vision and committed to putting out as editors say "a darn good paper".

Love to him and sorry for our loss,

Pam Parlapiano



Japan

With deep sadness, we have received the news of the demise of our fellow friend and the outstanding editor of **The STAR**, Mr. Emanuel Faria.

His consistent appeal, through his work as the editor of **The STAR**, for the actualization of a society without discrimination and prejudice against persons who have been affected by Hansen's Disease and restoration of their dignity, has reached out to the world. Owing to his persevering efforts, this world is advancing in the right direction one step at a time. His teaching will abide and we promise our fullest efforts for the further enhancement of **IDEA** and its activities.

With our deepest appreciation of Mr, Faria's longstanding efforts, we send our sincere condolences.

May his soul rest in peace

IDEA Japan Coordinator

Miyoji Morimoto



Ethiopia

We are very mournful when we heard of his death. We feel how weak and fruitless must be any words of ours which should attempt to comfort his family and co-workers from the grief of a loss so overwhelming. We pray that our Father may put his soul in heaven and may assuage the anguish of his family.

Please inform all his family, friends and co-workers of our mournful feeling at his death. Thank you

Sincerely yours

Birke Nigatu, ENAELP Chairperson

(10,000 member association of people affected by leprosy)



Japan

Yes he was an editor. When the news reached me, what I recall was him sitting behind his editor's desk, slightly leaning to the left with his right hand on the desk. He had everything that we expect an editor would have. We shall miss him.

Kay Yamaguchi, Sasakawa Memorial Health Foundation and IDEA, Japan



Nepal

Greetings from Nepal. All staff and executive members of **IDEA** Nepal are deeply saddened by the death of Emanuel Faria. We are really shocked and feel very sorry. All his contributions for "**The STAR**" are unforgettable. We would like to extend a heartfelt of condolences for his departed soul. We also would like to express our sympathy and love to the family and **The STAR** family.

Best wishes

Yashoda Jirel (Rajbhandari)
Nepal Country Coordinator and
the IDEA Nepal family



TO CARVILLE — THE HOSPITAL

by Ymelda Beauchamp

*I want to go back to that place
That sits amid the willows and old oak trees
That beautiful place that has a history
And a connection to many memories
I'm told that big house is still standing
Near Old Man River and the lake
This place that was a refuge to the sick and rejected
Now houses soldiers wearing green berets
I remember the forlorn whistle at dawn
Of the barges and big boats
Moving swiftly down the Mississippi
Like river ghosts dancing in the fog.*

*I long to walk the corridors once again
Of this home so far away
Of that shelter that protected me, healed my body
And still haunts my nights and days.*

*Love; do you remember the ardor of the jasmine
And the smell of honeysuckle after rain
The clamor of the wheelchairs in the hallways
And our laughter after pain?*

*Remember the Movie theater
And all the people in the canteen
The strong smell of coffee and chicory
And the songs you always sang to me?*

*Remember love, when we cuddled
In that place away from prying eyes?
We talked about our life, hopes and dreams
And everything under that sultry southern sky.*

*Remember the thunder that pierced the silence
In the stillness of our lonely nights?
And muffled our secret yearnings
For a better life on the outside.*

*Remember all the angels dressed in their white gowns
That understood our fears
They held us in their bosom
And dried up all our tears?*

*I want to see the infirmary once again
Where I spent so many days
This home that nurtured and sustained my early years
And still beckons me today.*

*I want to look back at the reflection
Of the young girl I used to be
A girl ablaze with love and passion
For all the things that would never be.*

*Please take me back to walk those hallways,
Hallways covered with white walls,
Walls that heard so many secrets
Some they kept some they told and some I know...*

*I want to see Carville, my sweet home away from home,
The beautiful place that witnessed suffering and profound hopes.
I want to go back to that home again that I left so long ago
Where people lived, cried and loved and now everyone is gone. . . .*

Fighting the Killers

by
Peter S. Pasqua

The door to the fight against the bacteria has a small window looking into a dark room. A computer lock with a special code secures it. As you walk in you can hear the vents above you sucking in air. Straight ahead is a full body suit that resembles Neil Armstrong's. Another door is opened and under a hood with negative pressure and filtered air passing over your head lies the killer of 3 million people a year. Tuberculosis.

Down the hall small hairless mice are being fed. Their little bodies are proportional except for one enlarged foot. It is large as their bodies and leaves them incapable of walking. They are laboratory test tubes that will live for six months like this. Then they will be tested with new drugs to treat the disease that is infecting their body. Leprosy

Tuberculosis and leprosy are being researched at the National Hansen's Disease Programs Center at the LSU School of Veterinary Medicine. The NHDPC is the former Gillis W. Long Hansen's Disease Center that is better known to the rest of the world as simple "Carville."

The Center used to be housed in Carville, Louisiana. Leprosy was researched and treated there for over 100 years. "It carries a lot of weight around the world because of all the work that was done in the past," Dr. Tom Gillis, Chief of Molecular Biology Research, said. But the research team moved to LSU in the early 90's and Carville closed their doors to new patients shortly after moving treatment to Summit Hospital.

Research of TB began in 1994. "We already had a biological Safety Level 3 Lab" and "TB and leprosy organisms are related," Dr. James Krahenbuhl, chief of Laboratory Research, said. According to Public Health Reports, 10,000 compounds a year are tested in, "drug development studies." In terms of specific projects people are working on and money allocated, "75-Percent of the branch's research is leprosy," said Gillis.

Leprosy research is tricky according to Discover. The bacteria cannot survive outside of the tissue. Therefore it must be cultivated in a host. "We study the disease in armadillos and nude mice,

" Gillis said. Through natural infection or artificial, researchers look at the immune system and how drugs affect the animal.

"You have to admire this organism from a biologist's point of view," Krahenbuhl said. It invades tissue but doesn't kill the host. This "well-behaved organism" grows to 10 billion in one gram of skin.

Funding for leprosy research is declining and the NHDPC is one of the few centers dedicated to it. "We are the world's expert on this disease," said Krahenbuhl. According to The Lancet cases of leprosy has become stationary at about 1 million, down millions from 15 years ago due to extensive treatment. "But something needs to be done differently if we are going to truly eradicate the disease," Gillis said.

Tuberculosis is a different story. Helped by the spread of HIV, which destroys the immune system, TB has infected a third of the world, according to Business Week. While only 10-percent of those are expected to develop the disease, drug-resistant TB is on the rise.

The federal government recently funded the NHDPC \$3.8 million for a five-year study testing compounds on TB. "It would be frightening if TB would become completely resistant to drugs," Gillis said, because of the huge amount of money that would be needed to treat people with newer drugs.

The compounds are tested on three levels. "See if it kills it, see if it is toxic in animals, then off to humans," said Gillis. "Gasoline" will kill TB but it is toxic, Krahenbuhl said. Of the 10,000 compounds tested a year, 90-percent are found ineffective.

According to Science, the genome of TB has been deciphered. "As we learn more about what constitutes our genetic makeup and how we respond to infection, then we'll understand why one person catches it and another doesn't," Gillis said. That applies to tuberculosis and leprosy. ★

Peter S. Pasqua
43272 Hwy 621
Gonzales, LA 70737

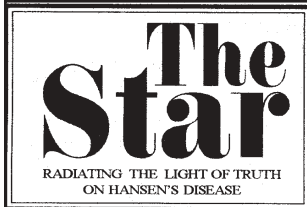
SOURCES OF HD TREATMENT IN THE UNITED STATES

THE NATIONAL HANSEN'S DISEASE PROGRAMS (NHDP) provides HD care to persons in the United States at 1770 Physicians Park Drive, Baton Rouge, LA 70816 and through the Ambulatory Care Program, which includes the following Outpatient HD Clinics

NATIONAL HANSEN'S DISEASE PROGRAM

AREA	FACILITY	ADDRESS	PHYSICIANS / NURSE	APPOINTMENTS
BOSTON	Lahey Medical Center	41 Mall Road Burlington, MA 01805	Samuel Moschella, MD Stephanie Burns, RN	781-744-5670
CALIFORNIA (Los Angeles)	LAC.USC Medical Ctr Attn: Section of Dermatology Room 8440	1200 North State St Los Angeles, CA 90033	Thomas Rea, MD Helen Mora, RN	323-226-5240
(Martinez)	Contra Costa Regional Medical Center Outpatient Clinic	2500 Alhambra Dr Martinez, CA. 94553	Sutherland/Saffier, MD's Eliso Judy, RN	925-370-5270 1-800-495-8885 (In State only)
(San Diego)	North San Diego Health Center	2400 Grand Ave San Diego, CA 92109	D A Lopez, MD Carmen Rodriquez, RN	358-490-4400
CHICAGO	University of Illinois College of Medicine Dept. of Dermatology	803 South Wood St Room 376 CME Chicago, IL 60612	Carlotta Hill, MD Ann Przepiora, RN	312-996-0734
MIAMI	Jackson Memorial Hospital	Ambulatory Care Ctr 1611 N. W. 12th Ave. Miami, FL 33136	Anne Burdick, MD Gloria Ingle, RN	305-585-2600
NEW YORK	Bellevue Hospital Ctr Dept of Dermatology Room 17-7	462 First Ave New York, NY 10016	William Levis, MD Aloys Cabrera, RN Louis Iannuzzi, PT, C.Ped	212-562-6096
PHOENIX	Maricopa County Health Dept	1825 E. Roosevelt St Phoenix, AZ 85006	Ronald Pusi, MD Bill Cooper, RN	602-372-6661
PUERTO RICO	University of Puerto Rico Medical School	Dept of Dermatology P.O.Box 365067 San Juan, PR 00936-5067	Pablo Almodovar, MD Sonia Santos-Exposito, RN	787-765-7950
SEATTLE	Harborview Medical Center	2 West Clinic - 359930 325 9th Ave. Seattle, WA 98104	James P Harnisch, MD Virginia Ouellet, RN	206-731-5100
TEXAS (Dallas)	Texas Dept of Health	2377 N. Stemmons Freeway Suite 5 Dallas, TX 75207-2710	Jack Cohen, MD	214-819-2010
(Houston)	Houston Health & Human Services Dept	La Nueva Casa de Amigos 1809 North Main Houston, Texas 77009	Terry Williams, MD Eileen Walton, RN	713-504-0256
(San Antonio)	Texas Center for Infectious Disease	2303 S.E. Military Dr San Antonio, TX 98223	Robert N. Longfield, MD Debbie Mata, RN	210-534-8857
(Harlingen)	South Texas Health Care Ctr OPCL	1301 Rangerville Road Harlingen, TX 78550	Richard Wing, MD Herb Tolentino, RN	956-423-3420 Ext- 351
OTHER SOURCES	State of Hawaii, Dept of Health 3650 Maunalei Ave. Suite 205 Honolulu, HA 96816 Phone: 808-733-9831	Mona Bomgaars, MD Mike Maruyama, Adm Lori Ching, PHN Fax: 808-733-9836		

FOR MORE INFORMATION: Call the NHDP at 1-800-642-2477 or Fax (225) 756-3806 — Email: MTemplet@hrsa.gov



PO BOX 325
POINT CLAIR BR
CARVILLE, LA. 70721

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 regis-

try 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 inside back page for 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 dapson. 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.

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.