

# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

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VOLUME 64 - 30**



**John R. Trautman MD**

Remembered page 3, photo courtesy National Hansen's Disease Museum

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*All correspondence concerning **The STAR** should be addressed to:*  
**Voiture Nationale**  
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**Indianapolis, IN 46205-2644**

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## **John R. Trautman, MD** **Revered in Life-- Remembered in Death, by Claire Manes PhD**

A Medical Officer in Charge wears stiffly starched uniforms and a demeanor to match. Dr. John R. Trautman wore his uniform with dignity and pride but memories and photos of him contradict any image of stiffness. In his duties he also appeared in Hawaiian shirts, sombreros, and golf attire with just as much command. As the longest serving MOC at the United States Public Health Services Hospital in Carville, Louisiana, (1968-1988), Dr. Trautman was the Medical Officer of Compassion and Common Sense. His service at the hospital as Clinical Director from 1960-1966 and as MOC is significant even today and is still fondly remembered.

Rear Admiral John R. Trautman, M.D. died in Spring Hill, Florida, on May 29, 2021, at the age of 93. The residents of Carville during his tenure called him “sterling...of the highest quality” and “friend,” supreme compliments from people keenly aware of their own rights and needs. He was acknowledged for his “humanity, kindness, and understanding.” (Dr. p.1)

The relationship was mutual. Dr. Trautman appreciated and respected the Carville community. He had served first as Clinical Director at the hospital from 1960-66 and returned in 1968 as the hospital director. Upon his 1968 return he greeted the Carville population acknowledging that he had held them in memory during his years away; they in turn paid tribute to him. Patients and staff rushed to greet him in the community theater and welcomed him with two standing ovations during his remarks. (Dr. 1)

In those remarks to the community the doctor made clear his interests: the well-being of HD patients and the eradication of the disease. To that end his years at Carville were marked by care for the patients, respect for his staff, engagement with the best minds in Hansen’s disease study, and innovations in drug therapy and research. Dr. David Scollard recalled Dr. Trautman’s kindness to him as a new staffer. He was very “welcoming and encouraging” to me. Scollard described Dr. Trautman’s tenure at Carville as “the golden era of Carville as a teaching institution” when international luminaries [such as] Drs. Paul and Margaret Brand and C.K. Job served on the staff, international visitors spent time there, and research on the armadillo began. Video teaching was another innovation during Dr. Trautman’s tenure; medical professionals on staff initiated the use of teaching videos to educate on site and beyond about the care and treatment of HD patients.

He also broadened the field of dermatological education. Dr. Samuel Moschella in a 1995 interview with Julia Elwood noted that it was Dr. Trautman who in 1970 opened the long running dermatological military training to civilian dermatology programs as well. Dr. Moschella acknowledged how that “helped very much with the early diagnosis of the disease. That’s how all the dermatology programs and professors became very sensitized to this place, allocating funds to send their Residents down here.” (Moschella)

His efforts, however, extended well beyond the 300 acres of Carville as he worked internationally, listening, researching, and educating on Hansen’s disease. Dr. Trautman was recognized as one of the leading authorities on HD. He met and collaborated with other scholars and advocates, regularly participating in the International Congress on Leprosy and meeting with world leaders and humanitarians including Indira Gandhi and Mother Teresa in India.

In his 1968 opening remarks Dr. Trautman committed to keeping the patients “uppermost in mind.” He declared his intent to do only what was in the best interest of the patients. “Certainly, no radical changes will be made unless you benefit from them.” (Dr. 1) Shortly after his service began, he quietly but firmly initiated this policy that patients must have considered as revolutionary but long overdue. He related the story years later in the documentary, *Triumph at Carville*. Dr. Trautman explained the event: a patient had escaped and Trautman was asked what should be done. (At that time escaped patients were routinely searched out and returned to the facilities. In earlier times they were sometimes jailed.) In answer to the question, Dr. Trautman said, “He’ll come back. We’re not going to go after him.”

José Ramirez further explained this process. He recalled that Dr. Trautman gave agency to the patients enabling them to come and go as they pleased with appropriate permission from their doctors. José described Trautman’s efforts as “walking a thin line between the patients’ rights and the ‘hard liners.’” (Ramirez) Mr. Pete Simien also recalled the pass

system. As he explained to Cassandra White, the pass system allowed “us to go out and look around and come back it makes you feel good.” As Pete saw it “we didn’t commit no crime.” (Simien)

Dr. Trautman achieved similar firsts on an individual level. José Ramirez in Carville during Dr. Trautman’s service credits the doctor and Mr. Vernon Bahlinger, social worker on staff, with enabling him to attend Louisiana State University as an undergraduate and graduate student while undergoing treatment for HD in Carville. Prior to that LSU had forbidden persons “with leprosy” from working at or studying on campus. The persuasive arguments made by the two men convinced the president of LSU to rescind that ruling, allowing José to achieve his degrees. Trautman and Bahlinger kept their activities private; José only discovered their actions years later when he had access to his hospital records. (Ramirez)

Julia Elwood, too, benefited from Dr. Trautman’s common sense approach. As a teen ager, Julia had been a patient at Carville and a student at the school. After her discharge from the hospital, she attended college and received her degree in English. In 1969 a teacher was needed at the Carville school. The principal, Mr. Gaston England requested permission to hire Julia for the position. Dr. Trautman’s comment was simple, “If she qualifies, hire her.” This simple act was radical; apparently, up to that time no HD patient had ever been hired for a position within the federal government. Julia later became principal and eventually Public Relations Director for the facility. Dr. Trautman declared her the “best damn PR person the hospital ever had.” (Ramirez)

The life of the hospital community was important to Dr. Trautman who sat in on meetings of the many clubs and organizations founded by the patients. Ray Elwood recalled that Dr. Trautman, uninvited, attended meetings to listen and learn about the interests and needs of the patients. (Elwood) By contrast in 1925 patient Gabe Michael invited then MOC Dr. O.E Denney to attend a meeting of the What Cheer Club (later the Patient Federation). (Manes) Dr. Trautman needed no invitation, his concern for the patients was his calling card. José Ramirez concurred with Ray’s recollections. He recalled that when he had occasion to visit with Dr. Trautman about Patient Federation business the doctor would always sit next to [me] and not behind his desk to discuss patients’ issues. (Ramirez)

The doctor especially esteemed the work of The STAR. He was particularly attuned to its international value. In his first address to the community in 1968 he made clear his intentions regarding the publication. “The only business I want to mention today is the STAR. I would like very much to see this publication continue and continue as your publication.” (Dr. 1) His remarks were encouraging because only a few months earlier Stanley Stein the founder and champion of The STAR had died. The remarks were also intentional. As Dr. Trautman’s daughter Patti Jachimowicz recalls, Stanley Stein had called her father before he left San Francisco for Carville requesting a meeting with Trautman when he reached the hospital. Stanley died in December 1967 so the meeting never transpired, but Dr. Trautman had always felt that Stanley wanted to ensure that his work would continue. It survived and continued to be recognized. (Jachimowicz)

Ray Elwood recalled that Dr Trautman would show up unannounced at The STAR office. There he talked about The STAR’S significance as a great resource for researchers worldwide and for thousands of people institutionalized in other leprosarium. At his retirement Dr. Trautman elaborated on that belief. “I believe it is among the most important publications which now exists. If you take into consideration all the publications on HD, it is the most widely read. In addition, The STAR can publish and circulate information quickly to all parts of the world and much of the credit has to go to the wonderful help which the Forty and Eight, a US veterans’ organization, has given.” (Dr. Trautman, p.15) He proved his esteem in his own efforts to “radiate the truth of Hansen’s disease” as Julia Elwood noted, “He worked to reword Public Health Service manuals referring to HD. The term which has been advocated by The Star magazine since 1941 is now officially accepted by the PHS.” (Elwood, Julia )

Dr. Trautman’s compassion for the men, women, and children he served may have begun even before his medical studies and career. As a young boy with his father, he witnessed HD patients undergoing the “fever treatment” in “hot boxes” a brutal and ultimately unsuccessful treatment that patients desperate for a cure endured. The experience must have impressed him deeply since in later years he recounted the event to his daughter Patti.

Memories from those touched by Dr. Trautman tell part of the story, but archival pictures enhance it. The doctor wore his uniform with pride but he appeared equally comfortable in a Hawaiian shirt at a patient celebration, in a golf cart at the Invitational Golf tournaments, in the ballroom at Mardi Gras, and in a sombrero for a Mexican gala. Pictures indicate that he also took pride in the work of others and proudly awarded commendations to many for work well done.

Dr. Richard Truman who was on Dr. Trautman's staff called him a "strong leader and a great people person [who] cultivated personnel. Truman remembered that Dr. Trautman whose accomplishments in treatment and research for HD were monumental and whose awards were many was most proud of the Equal Employment Opportunity award that he had received because of his work with and for others. According to Dr. Truman that award was the "hardest to come by and the most meaningful to him. [He] was all about people, giving them opportunity and bringing them along."

He met worldwide with those in the HD community, but archival photos record meetings closer to home with New Orleans, Louisiana, Archbishop Philip Hannan; Baton Rouge, Louisiana, Bishop Stanley Ott; Louisiana Governor John McKeithen, and Louisiana Representatives Lindy Boggs and Gillis Long with California Representative Henry Waxman. What was important to the patients and staff at Carville was important to him and his presence certified that. Deceased patient Mary Ruth Daigle once told me that sometimes the doctors would come to the patients' weekly movies and sit in the back. Dr. Trautman was in the midst of the activities spearheaded by the residents and staff.

He was a loyal and faithful leader of the Carville facility but he was also a lover of sports and an ardent fan of the LSU Tigers football team, always convinced of their prowess. Patti recalls that after particularly close games when she knew her father was fretting the outcome, he would call her and claim that he knew "all along" that the Tigers would win. His wicked sense of humor is also valued by Patti who is grateful that her father kept that until his demise. Carville called him, "Friend." Patti called him "Dad." Both names were proudly claimed by him.

Anyone under a doctor's care desires a person with expertise in the art and science of medicine. They also hope for doctors with compassion and a willingness to listen. Carville residents found all of that in Dr. Trautman. "Well done good and faithful servant." (Matthew 25:23)

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#### Editor's Note

*Dr. Trautman became Director one year prior to my admission to Carville but he had already cemented a favorable impression with the patients before his appointment. I met with him in his office at the "old mansion" where the administrative offices were housed to discuss allegations that I had violated hospital policy by inviting an LSU intramural softball team to play a game against a group of patients. I feared a reprimand from Dr. Trautman, but he believed my explanation and concluded that no such policy was violated as the front gate guards had a written OK from one of the administrators. Dr. Trautman and the hospital Social Worker later advocated on my behalf with LSU administrators who agreed to reverse a university policy about "not allow persons with leprosy to work or attend the university as a student." His intervention made it possible for me to attend LSU while also a patient. He helped change my life and I loved him for his courage and common sense.*

—José Ramirez, Jr.

## A 'fabulous' life: For Makia Malo, the obstacles of Hansen's disease led to a personal triumph By Valerie Monson

"Despite the separation from family, it was a fabulous life and it was a fabulous world."

So pronounced Makia Malo as he greeted everyone at a meeting of Ka 'Ohana O Kalaupapa in 2015. Those were unlikely words from someone diagnosed with leprosy who was taken from his family as a boy and sent to Kalaupapa where he would lose his eyesight and suffer other physical disabilities. Yet, for Makia, all of those obstacles would lead to personal triumph. He would go on to graduate from the University of Hawaii-Manoa, travel the world as an acclaimed storyteller and poet, deliver a chant at the United Nations and create a scholarship for young Hawaiian students in need of a helping hand.

Makia died earlier this month at the Kuakini long-term care facility on Oahu. He was just shy of his 87th birthday.

His fabulous life will live on in the hundreds or thousands of people he touched with his kindness, humor and determination.

"Being with Makia is something I will never forget," said Sheldon Loui, social worker at Leahi Hospital in Honolulu from 1999 to 2016 where Makia often stayed in a wing designated for Kalaupapa residents. "He was always in a good mood, he never felt sorry for himself. He just embraced life. Makia was happiest when he was interacting with people; he always wanted to be around people."

Makia Malo was born in Papakolea on Oahu, one of nine children, where he was called by his English name of Elroy. The Malo family was devastated by leprosy as, one by one, four youngsters would be sent to Kalaupapa. Makia's mother would later be diagnosed with the disease and admitted to Hale Mohalu in Pearl City.

When Makia was flown to Kalaupapa in 1947, not quite 13, his early fears were tempered when he was greeted at the airport by his sister, Pearl, and welcomed by older brother Bill and his cherished younger brother, Earl, who Makia called Pilipili.

It was a time of change for people affected by leprosy. Medicine had been discovered that was giving people hope. Two years later, Hale Mohalu opened, and laws were revised so that people could choose to reside at Hale Mohalu as an alternative to Kalaupapa.

### Gaining an education

Another opportunity at Hale Mohalu: school. When a doctor encouraged Makia to enroll, he dismissed the idea, not wanting to leave his siblings. But his sister convinced him otherwise.

"She said the one thing that would get to me," said Makia during a series of interviews with this writer. "She said, 'Think how proud Mommy and Daddy would be.'"

So off he went. Makia found that he not only excelled in the classroom, he loved everything about learning. He graduated in 1952 as valedictorian. In the crowd to watch Makia receive his diploma in his tuxedo were his family, proud indeed.

Makia returned to Kalaupapa where he continued to enjoy life until he saw the disease changing his body. He was not responding to the medicine like others had. Every time he looked in the mirror, he noticed something different. Finally he realized the disease was now taking his eyesight. He began drinking heavily and became angry and belligerent.



**Makia Malo and his wife, Ann, at the 1997 opening ceremony of the "Quest for Dignity" exhibit at the United Nations. Makia blessed the exhibit, delivered a chant and helped untie the maile lei with UN Secretary General Kofi Annan. (Photo courtesy of Valerie Monson)**

Barely 30 years old, Makia Malo was blind. Back at Hale Mohalu, he realized he had to take charge of his new life or sink into despair. The answer to his prayers came in talking books. He became obsessed with his new world and found a new purpose.

“I would just read and read and read for days straight,” he said.

He was told about a writing contest and, feeling better about himself, decided to enter. It was the breakthrough he needed: Makia’s story won first place. He received congratulations from Congresswoman Patsy Mink and a call from Ho‘opono Services for the Blind where he started to see in another way.

“I began to realize many of the fears I had were of my own,” said Makia.

The next year, 1972, he enrolled at UH-Manoa at the age of 37 where there may never have been a more enthusiastic student who couldn’t wait for homework.

“It was so fabulous! Wanting to learn, being introduced to all this!” he remembered before suddenly turning somber. “But it was like I was carrying a torch for all the people in Kalaupapa. I was remembering my kid brother who died here and never had the chance (to go to college).”

Makia was not only blind, but because his fingers had been damaged by the disease, he was unable to read Braille. To learn, he had to listen to people who would read him his lessons or he would replay lectures on tapes. To take tests or write papers, he would need to dictate.

Ki‘ope Raymond, now a retired professor of Hawaiian Studies at Maui College, was one of Makia’s readers. They were both studying ‘olelo Hawaii, the Hawaiian language.

“I was just in my early 20s and some of my most vivid memories I have with Makia are what shaped me as a human being,” said Ki‘ope. “Makia was so gracious and one of the smartest guys on a broad range of subjects.”

Sheldon Loui believes that Makia was the only Hale Mohalu graduate who went on to graduate from UH-Manoa.

### **Professional storyteller**

After that, nothing could stop Makia. He was invited to join a group of professional storytellers which would take him and his wife, Ann, around the world. He became interested in community theater and dictated poems to Ann. He had seeing eye dogs that gave him even more independence. His new favorite word: “fabulous.”

Makia not only entertained his many audiences, but educated them as well. He was deeply offended by use of the word “leper” and actively spoke out against it. He and Ann wrote essays about how much that hurtful term should no longer be part of the lexicon.

In 1997, Makia was invited to the United Nations along with other Kalaupapa residents, for the opening of the exhibit, “Quest for Dignity,” that was filled with positive images and the words of people who had experienced leprosy around the world. Makia gave the opening chant and helped untie the maile lei with UN Secretary General Kofi Annan.

A lifelong member of the Church of Jesus Christ of Latter-day Saints, Makia found inspiration in Father Damien and attended both the beatification and canonization ceremonies for the saint in Europe. With broadcast journalist Pamela Young, he wrote a memoir, “My Name is Makia.” He became a founding member of Ka ‘Ohana O Kalaupapa and served on the board of directors for nearly 10 years.

Still, Makia felt the need to give back.

“I would always think about my kid brother,” he said. “When I go home to Kalaupapa, I walk past the grave and I call out his name. I talk story. I think about him and so many of the others — Donkey, Tony, Lahela, Charlie — all these young kids who never had the opportunities that I did. So many died.

“That’s what pushed me to start the scholarship.”

Malo’s scholarship, first awarded in 2002, provides assistance to young Hawaiians who want to become doctors, lawyers or dentists.

It’s another way that the life of Makia Malo will live on.

# The Long Road to Multidrug Therapy for Hansen's Disease

by Tom Adams, R.Ph.

"The road is long with many a winding turn that leads us to who knows where, who knows where, but I'm strong, strong enough to carry him. He ain't heavy, he's my brother." These lyrics of a song popular in the United States in 1969 are applicable to the long road of drug therapy that has culminated in Multidrug Therapy (MDT) for Hansen's disease (HD). This article will address some stops along the road where determined clinicians, scientists, the United States Public Health Service, and the World Health Organization carried the load for their brothers and sisters and achieved milestones in the quest for effective and safe drug therapy of HD.

Before the introduction of antibiotics, many chemicals and compounds were unsuccessfully employed as "cures" for HD. For centuries, Chaulmoogra Oil, an extraction from the seeds of *Hydnocarpus wightiana* was applied topically for HD treatment. Following its introduction to Western medicine in the early nineteenth century, therapy with the oil progressed from topical and oral administrations to injections.

In 1920 the publish work of Walker and Sweeney theorized an explanation for the efficacy of Chaulmoogra Oil, somewhat validating its centuries-long use for HD therapy. Remarkably, their conclusion "with reasonable certainty that any therapeutic action which Chaulmoogra Oil may have in leprosy may be due to its direct antiseptic and bactericidal action" validated the use of the oil for HD therapy. [*Morrow 1922*]

Whether taken orally (as drops or encapsulated) or injected, Chaulmoogra Oil was fraught with undesirable side effects. As Stanley Stein, editor of *The Star*, noted in *Alone No Longer*, "The oral doses were nauseously given out in the cafeteria at mealtime". He also noted "the after effects were sometimes frightful-painful, suppurating abscesses which the Chaulmoogra Oil would generate in the patient's backside."

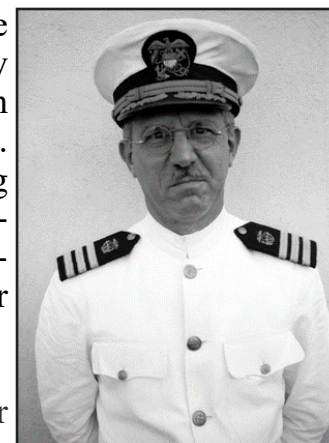


Alice Augusta Ball

In the early 1900s the work of Alice Augusta Ball, a 23 year-old young chemist at the University of Hawaii, revolutionized Chaulmoogra Oil therapy. [*Worthen*] Ball developed a process to make the active ingredients of the oil water soluble, able to be injected intramuscularly, and be readily absorbed. For the next twenty years until the advent of sulfonamides, this would become the world's primary HD treatment. By 1918, 78 people with HD at Kalihi Hospital who had received this treatment were free of lesions, and discharged from the hospital. [*Parascandola, 2003*]

In 1940, Dr. Guy Henry Faget became medical officer in charge of the United States Public Hospital at Carville, Louisiana. Among many qualifications, the Public Health Service labeled Faget a specialist in tuberculosis (like HD a disease also caused by a mycobacterium).

Based upon his previous clinical experiences with the sulfonamide drug Sulfanilamide, he began experimenting with it for HD therapy in volunteer patients. The toxicity of Sulfanilamide proved considerable and its effectiveness was limited resulting in a conclusion that Sulfanilamide could not be regarded as a curative agent for HD lesions.



Dr. Guy Henry Faget

After hearing of success with a sulfone (Promin) in rats, Faget began to recruit volunteers for Promin therapy. In the Christmas 1941 edition of *The Star*, Faget made his recruitment appeal directly to Carville patients with the following words of encouragement:

***This is the Modern Age, the Age of Light. Let us have the truth. Leprosy is not a dirt disease. Leprosy is not due to any sin committed by those who contract it. It is not a retaliation of God against its victims. Leprosy is a germ disease just as tuberculosis, typhoid fever and pneumonia are germ diseases. It is no more shameful***



*to be infected with the germs of leprosy than with those of tuberculosis, typhoid or pneumonia. So why discriminate against one of these diseases? Ignorance is the answer.*

*Therefore, let us all cooperate and pull together—the patients and personnel. Together we will succeed; divided we will fail. Yes, the day shall come when the dread of leprosy too will pass away just as it did for yellow fever, cholera and tuberculosis. Let us have courage; We are making strides forward and upward, out of the valley of darkness, over the mountains of difficulties, and into the sunshiny plains of tomorrow.*



The first successful drug treatment for HD involved daily intravenous drug injections with a large gauge needle.

After six months of Promin therapy there was improvement in lesions among patients. Faget's successes led to Promin therapy being labeled "The Miracle at Carville," marking the first time that there was legitimate hope for an effective treatment and cure of HD. Promin could be safely administered with monitoring by blood and urine testing. Faget continued studies with other sulfones, including Diasone and Promizole. In 1946 he published studies documenting the demonstrated efficacy of these two drugs. [ILA]

Promin was administered intravenously. In 1947 Promin's parent compound Dapsone, initially thought to be too toxic through intravenous administration, was administered subcutaneously. By 1951 Dapsone was made available in tablet form and became the accepted monotherapy as a twice daily oral dose employed worldwide until the early 1980's.



"Blister Packs" of MDT

While the bactericidal properties of Dapsone were effective against HD's causative *Mycobacterium leprae*, primary (treatment) relapses and secondary (resistance) relapses began to emerge in the 1970s in nearly 20 percent of patients. In 1976 the World Health Organization (WHO) addressed Dapsone resistance by establishing the Special Program for Research and Training in Tropical Diseases. As a result, in 1981 two drugs (Clofazimine and Rifampicin) were added to Dapsone to become Multidrug Therapy (MDT).

Clofazimine had been used as monotherapy in the early 1960s through the mid-1970s. Clofazimine is bacteriostatic and slowly bactericidal limiting growth or reproduction of *M. Leprae*, similar to Dapsone. The drug is associated with increased skin pigmentation though discoloration will gradually disappear with cessation of therapy.

Rifampicin, named Rifampin in the United States, was first used and today remains a preferred treatment for tuberculosis. Rifampicin is a powerful bactericidal agent against *M. Leprae*.

By the 1960's it was recognized that the varied clinical responses to HD were dictated by the patient's immunologic response. Doctors Ridley and Joplin developed a classification system to cover the spectrum of HD clinical presentation. [Ridley, Joplin 1966] At one end of the spectrum is polar tuberculoid disease (TT) with rare presence of bacteria, and at the other is polar lepromatous (LL) with a large number of bacteria. (Of note is that most patients were deemed borderline because they fell somewhere between the extremes of the spectrum.) [Pardillo, et.al.] In 1981, WHO simplified the classification and recommended a classification for operational purposes as pauci-bacillary and multi-bacillary (PB and MB).

Today HD patients with strong immunity and few bacteria are referred to as patients with PB and those with many bacteria are referred to as MB. In 2017 WHO revised the definitions of PB and MB disease to define PB as a case

of the disease with 1-5 skin lesions, and MB a case of the disease with more than 5 lesions or with nerve involvement.

The classification system was initially used to determine drug therapy. Where the patient fell on the spectrum dictated content and duration of MDT. In 2018, WHO changed its recommendation from Rifampicin and Dapsone for PB to the same 3-drug regimen used for MB (Rifampicin, Dapsone, and Clofazimine). The stated intent was to avoid under-treatment of MB patients misclassified as PB patients. WHO set the duration of therapy as 6 months for PB and 12 months for MB cases. (The National Hansen's Disease Program recommends 1 year therapy for PB cases and 2 years therapy for MB cases.) [HRSA/NHDP]

Other antibiotics have been successfully substituted for cases of resistance to one or more of MDT drugs, These include Minocycline (substituted for Dapsone), Clarithromycin (substituted for any of the three drugs), Levofloxacin (substituted for Rifampicin). All of these are common antibiotics, readily available since each is used to treat common infectious diseases. [Chauhan 2020]

Unfortunately, about 50% of HD patients experience either reversal reactions (RR) or Erythema Nodosum Leprosum (ENL) during the course of their disease and will need drug therapy. RR treatment options range from Non-Steroidal Anti-inflammatory Drugs to Prednisone or Clofazimine depending on severity. Depending upon severity, ENL treatment options include analgesics, Prednisone, Clofazimine, Methotrexate, or the drug of choice, Thalidomide. [HRSA/NHDP]

The winding turns of drug therapy straightened as dedicated scientists and clinicians achieved effective drug therapy. The WHO has provided free MDT since 1995. As of 2020, more than 16 million HD patients have been treated with MDT. Even though MDT is provided free of charge, in many countries where HD is endemic, availability to the patient is not a "given." Additionally, stigma and cultural influences remain obstacles to HD patients and can adversely impact timely treatment potentially leading to physical disabilities. Continuing diligence is needed to meet the formidable challenge of getting MDT to all those who require it.

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## “Penikese Island Leprosarium in Massachusetts: 1905-1921”

by Paul Manage Johansen

Readers of The Star know the stories of Carville and Kalaupapa, but perhaps not of Penikese.

From November, 1905 to March, 1921 Massachusetts administered a hospital for people who experienced Hansen’s Disease (known at the time as leprosy), on the barren 74-acre island of Penikese in Buzzards Bay, midway between Martha’s Vineyard and New Bedford. During those 16 years the hospital cared for 36 patients at great expense, only three of whom were born in the United States. For them the hospital was also a prison.



Prior to 1900, only nine cases of Hansen’s Disease had ever been recorded in Massachusetts, the first in 1825. But three cases appeared in 1904 and another two in 1905. The public outcry was swift and loud: take them away! But where? The State Board of Charity was empowered to find a suitable location. Current medical and legal opinion could not have been clearer: people with Hansen’s Disease should go to the State Hospital in Tewksbury, which treated other infectious diseases “dangerous to the public health” including tuberculosis, typhoid fever, smallpox, scarlet fever and measles.

But the hospital trustees would not admit them: “We feel we should be neglectful of our duty should we consent to such transfers, thereby exposing fifteen to eighteen hundred inmates more or less to that much dreaded disease. We also feel confident that the action we have taken will be sustained and approved by the Public.”<sup>1</sup> After repeated efforts, including a letter from the Massachusetts Attorney General, the State Board of Charity eventually gave up and looked elsewhere.

The Board purchased a farm in Brewster on Cape Cod, where summer tourism was beginning to flourish. Again, the public cried out; a petition against the proposal quickly received 351 signatures. At a public hearing at the State House in Boston, “It was argued that whether [Hansen’s Disease] was highly contagious or not, the people believe it to be so, and consequently no one with any choice would come by preference to a district where a colony...was located. Thus taxable values would fall.”<sup>1</sup> A judge testified, “I am full of sympathy for them. My heart is warm for them but I, for one, do not want to see them on Cape Cod.”<sup>1</sup>

Fear of people who experienced Hansen’s disease was inextricably connected to fear of immigrants. According to a 1916 administrative report, “It seems reasonably certain that the disease is not endemic [to Massachusetts] since every case discovered thus far has shown a history indicating foreign origin...The disease as a problem for the community therefore is inseparably connected with immigration from those districts and territories where it is prevalent.”<sup>1</sup>

After other failed attempts, and in spite of further protests, on July 18, 1905, the Board finally purchased Penikese, the smallest and remotest of the Elizabeth Island chain. Penikese “forms the tip of the Spur which extends back from the heel of Cape Cod” and has “an outline not unlike that of the crook-necked squash.”<sup>1</sup> On November 17, 1905, the first five patients arrived, four men and one woman ranging in age from 23 to 38 years. All five died and are buried on Penikese.



The first Superintendent of Penikese, Louis Edmonds, MD only lasted one year on remote Penikese. Fortunately for the patients, he was replaced on January 1, 1907 by Frank Parker, MD and his wife Marion, who spent the next fourteen years trying to fulfill every reasonable wish the patients had. They faced these challenges with courage and optimism, putting the needs of their patients ahead of their own. Island life was not easy, especially in the winter, particularly for patients who did not speak English.

“If one reflects...upon the effects of loneliness on robust, well nourished, and easily contented laborers, some insight is readily gained into the broodings of the [person experiencing Hansen’s Disease], ill as he is, racked often with rheumatic pain and burning with...fever, a person without hope, committed

against his will to this no-man’s land, so empty of all the sounds and associations that his experience in life has made companionable and comforting to him.” 1

From its inception in 1905, it was hoped Penikese would only be temporary. According to the 1917 Annual Report: “As early as 1904 the State Board of Charity has sought to interest Federal authorities in the advisability of Federal care and treatment of all [people who experience Hansen’s Disease] found in the United States. The equitable basis for this view is that [Hansen’s disease] in this country has always shown itself to be a by-product of immigration. Furthermore, it is obvious that a centrally developed system of care and treatment by the Federal government, with a background of long experience in the care of [people who experience Hansen’s disease] in Hawaii and the Philippines, must certainly be more effective and more economical than occasional and temporary care provided by local State authorities, driven thereto by clamorous and inconsiderate public opinion. Many other States have joined Massachusetts in advocating this step, until, in February, 1917, the 64th Congress enacted a law providing for Federal assumption of this burden.” 2



**Penikese Graveyard**

“An Act to Provide for the Care and Treatment of Persons Afflicted with Leprosy and to Prevent the Spread of Leprosy in the United States” was approved by Congress on February 3, 1917. The 1918 Annual Report mentioned that “The war has prevented the speedier execution of this statute. It is now hoped that progress will be made toward Federal assumption, and that the excessively expensive plan of an island institution for numbers that are so small may soon be given up.” 3 But Carville would not become a federal leprosarium until 1921. The federal government purchased Carville from Louisiana January 3, 1921; the US flag was raised February 1, 1921. And on March 10, 1921, the last 13 patients at Penikese were sent to Carville.

Massachusetts tried unsuccessfully to sell Penikese. Eventually all island buildings were burned and the cement walls and foundations were dynamited. Over its 16-year history, Massachusetts had spent a total of \$378,329.21 to care for 36 patients on Penikese, or about \$42.91 per week per patient. That figure was nearly 20 times what it would have cost to care for these patients at the State Hospital in Tewksbury. Citizens paid dearly for their deep-seated fears of Hansen’s disease and immigrants. As the medical historian Philip Kalisch observed, “[Hansen’s disease] was one of the first diseases to successfully command complete tax supported institutional care for its victims at no cost whatsoever to them except their freedom.” 4

Two Massachusetts authors have recently begun rewriting the story of Penikese from the perspective of the patients’ lived experience. Penikese serves as the backdrop for *Beyond the Bright Sea* 5 (2017) by Lauren Wolk, a young adult book that won the 2018 Scott O’Dell Award for Historical Fiction. The protagonist, Crow, washes up in a small boat on the shores of Cuttyhunk Island in 1913 and is raised by an old man with a soft heart. By age twelve Crow starts wondering where she came from, and learns of the former leprosarium on neighboring Penikese. Convinced she was set adrift by patients there, and that she may have an older brother, she triggers “an unstoppable chain of events...down a path of discovery and danger.” 5



**Dynamited Foundations**

In 2010 Eve Rifkahn published *Outcasts* 6, “a docu-drama in verse” structured into a Prologue, four Acts and an Epilogue. Her poems combine historical research with vivid imagery, bringing most of the patients to life in a unique way. In a prescient foreshadowing of things to come a century later, “1918 – The Angel of Death Walks in the World Outside” describes what it was like to live on a remote island during the 1918 flu pandemic; the prison home suddenly transformed into an unlikely safe haven. This poem ends: “and the patients on the tiny island / cast away cast out forbidden / look at each other in wonder / at all

the world turned upside down” Here is one poem in its entirety (Isabelle and “The Chinaman” were two of the 36 patients cared for at Penikese):

**The Leprosarium**  
is our world  
we are the lords of bracken and moraine  
we name Isabelle the queen  
her throne lichen-crusting granite  
cormorant feathers for a crown  
and you knights and ladies  
of this kingdom by the sea  
forget brothers or wives rend the ties  
as rabbis cut the fabric of grief  
crazy or sane in the land of leprosy  
bodies dwindle but not our hearts  
let us invent each other  
Chinaman sing us a song  
~Eve Rifkah 6



**Laundry Room**

On October 21, 2021 the Public Health Museum in Tewksbury – located on the grounds of the same State Hospital which refused to admit the first patients with Hansen’s disease – commemorated the centennial of Penikese closing in 1921 with a panel discussion featuring The Star’s Editor-in-Chief, Jose Ramirez, Jr., former Director of the National Hansen’s Disease Program in Carville, David Scollard, and journalist Ken Hartnett. The panel can be viewed online at [www.youtube.com/watch?v=Np7UtcJBb7A](http://www.youtube.com/watch?v=Np7UtcJBb7A). As of this publication date, the Public Health Museum is in the process of developing an online exhibit, “Penikese Island Leprosarium and the Real Story of Hansen’s Disease”, which will be accessible at [www.publichealthmuseum.org](http://www.publichealthmuseum.org).

To learn more about Penikese, please email author Paul Johansen at [iguanaphoto@gmail.com](mailto:iguanaphoto@gmail.com) and/or look for these resources:

- 1) “State Care and Treatment of Lepers in Massachusetts,” by the Secretary of the Massachusetts State Board of Charity, February 26, 1916.
- 2) Thirty-Ninth Annual Report of the State Board of Charity of Massachusetts for the Year Ending November 30, 1917, Wright and Potter Printing Co.
- 3) Fortieth Annual Report of the State Board of Charity of Massachusetts for the Year Ending November 30, 1918, Wright and Potter Printing Co.
- 4) Philip Kalisch (Sept-Oct 1973), “A Comparative Analysis of Societal Response to Leprosy in New Brunswick, 1844-1880, and Massachusetts, 1904-1921,” Bulletin of the History of Medicine, vol 47, no 5, pp 480-512.
- 5) Lauren Wolk (2017), Beyond the Bright Sea, Puffin Books. Winner of the Scott O’Dell Award in Historical Fiction: “a gorgeously crafted and tensely paced tale that explores questions of identity, belonging, and the true meaning of family” (from the book jacket). You may contact Ms. Wolk at [lwolk@cultural-center.org](mailto:lwolk@cultural-center.org).
- 6) Eve Rifkah (2010), Outcasts, Little Pear Press. You may contact Ms. Rifkah at [erifkah48@gmail.com](mailto:erifkah48@gmail.com).
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## New Face Book Group Encourages Remembering Carville by Anne Britt

In 1999 the Hansen's Disease hospital in Carville, La. was moved to Baton Rouge, Louisiana, and the state of Louisiana took over the property for a National Guard program for at risk youth. Some patients and the Daughters of Charity remained on the grounds for several more years. Today the only remnant of the long history of HD in Carville is the museum. Despite Covid, curator Elizabeth Schexnyder continues the work of educating the public about Hansen's disease: the men, women, and children isolated there; and the religious, military, and lay workers who served at the site. Once the museum reopens after Covid, Elizabeth will once again be able to invite people to tour the facility and learn about HD in Louisiana and around the world.

Although the hospital is closed, the grounds are still sacred territory for those who lived there or had relatives as patients. In that spirit a new group, Friends of the Carville Historical District has formed to support and promote the work of the museum and to assure that the story of Carville is told correctly. To date the group, spearheaded by Anne Harmon Britt, whose parents were patients in Carville has developed a Face Book page Friends of the Carville Historical District. It is open to any and all who want to participate in remembering the Carville story or learning about it.

Post Covid, the group hopes to do more to educate the public about HD through tours of the facility, reunions of folks connected to the hospital and ongoing news about HD. Just recently a Friends member invited interested Face Book participants to join in a zoom panel about HD patients from Pekinese Island, Massachu-

setts, who were transferred to Louisiana in 1921 when the Louisiana Home was taken over by the federal government. This outreach is one example of the education that can help to recover and respect the lives of so many who tread the grounds in Carville, La.

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

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Physician – Dr. Jessica Fairley  
email: [jessica.fairley@emory.edu](mailto:jessica.fairley@emory.edu)  
PH: (404) 686-5885  
Public Health Nurse: Jennifer Breiman, RN  
email: [Jennifer.breiman@emoryhealthcare.org](mailto:Jennifer.breiman@emoryhealthcare.org)

### **BOSTON HD CLINIC**

Lahey Medical Center  
41 Mall Road  
Burlington, MA 01805  
PH: (781) 744-5670 Fax: (781) 744-5687  
Physicians - Dr. Julia Benedetti / Dr. Winnie Ooi  
email: [julia.benedetti@lahey.org](mailto:julia.benedetti@lahey.org)  
email: [winnie.w.ooi@lahey.org](mailto:winnie.w.ooi@lahey.org)  
Public Health Nurse - Stephanie Burns, RN,  
D.N.C.  
email: [stephanie.a.burns@lahey.org](mailto:stephanie.a.burns@lahey.org)  
PH: (781) 744-5670

### **CHICAGO HD CLINIC**

University of Illinois at Chicago  
Outpatient Care Center (OCC)  
1801 W. Taylor Street, Suite 3E  
Chicago, IL 60612  
PH: (312) 996-8667 Fax: (312) 966-1188  
Physician - Dr. Carlotta Hill  
email: [chhill@uic.edu](mailto:chhill@uic.edu)  
Public Health Nurse Yusuf Adegoke, RN  
email: [yadegoke@uic.edu](mailto:yadegoke@uic.edu)  
PH: (312) 996-0734

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LAC+USC Medical Center  
1100 North Start St. Clinic Tower A5B123  
Los Angeles, CA 90033  
PH: (323) 409-5240 Fax: (323) 441-8152  
Primary Physician/Dermatology -  
Dr. Maria T. Ochoa  
email: [maria.ochoa@med.usc.edu](mailto:maria.ochoa@med.usc.edu)  
Public Health Nurse - Jeffrey Phommasith, RN  
email: [jphommasith@dhs.lacounty.gov](mailto:jphommasith@dhs.lacounty.gov)  
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1611 N.W. 12<sup>th</sup> Avenue  
ACC East – 2<sup>nd</sup> Floor  
Department of Dermatology  
Miami, FL 33136-1096  
PH: (305) 585-2511 / (305) 585-7348  
Fax: (305) 355-2155 / (305) 585-6397  
Primary Physician - Dr. Andrea Maderal  
email: [AMaderal@med.miami.edu](mailto:AMaderal@med.miami.edu)  
Public Health Nurse - Liliana Zucki, RN  
email: [Hansen-Program@jhs.miami.org](mailto:Hansen-Program@jhs.miami.org)  
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Department of Dermatology  
462 First Avenue, Room 17-N-7  
New York, NY 10016  
PH: (212) 562-5670 Fax: (212) 263-6423  
Primary Physician - Dr. William Levis  
email: [doctorwilliamlevis@gmail.com](mailto:doctorwilliamlevis@gmail.com)  
Public Health Nurse - Zina Jones, RN  
email: [Zina.jones@nychhc.org](mailto:Zina.jones@nychhc.org)  
Telephone: (212) 562-5581

### **PHOENIX HD CLINIC**

Wesley Community Center Inc.  
1300 South 10th Street  
Phoenix, Arizona 85034-4516  
PH: (602) 372-2039 Fax: (602) 372-3862  
Primary Physician - Dr. Ronald Pust  
Tucson Office: (520) 626-5650  
email: [rpust@email.arizona.edu](mailto:rpust@email.arizona.edu)  
Public Health Nurse - Lisa Carranza, RN  
PH: (602) 257-4323  
email: [lcarranza@wccphx.net](mailto:lcarranza@wccphx.net)

### **SAN JUAN HD CLINIC**

University of Puerto Rico Medical Sciences  
Campus  
School of Medicine - Dept. of Dermatology  
P. O. Box 365067  
San Juan, PR 00936-5067  
PH: (787) 765-7950 Fax: (787) 767-0467  
Primary Physician - Dr. Aida L. Quintero Noriega  
email: [dermatol.rcm@upr.edu](mailto:dermatol.rcm@upr.edu)  
Email: [aida.quintero@upr.edu](mailto:aida.quintero@upr.edu)  
Public Health Nurse - Sonia Santos-Exposito, RN  
PH: (787) 758-2525, Ext. 5503  
email: [sonia.santos@upr.edu](mailto:sonia.santos@upr.edu)

### **SEATTLE HD CLINIC**

Harborview Medical Center  
2 West Clinic – 359930, 325 Ninth Avenue  
Seattle, WA 98104  
PH: (206) 744-2212  
Fax: (206) 744-5174  
Physician - Dr. James Harnisch  
email: [jpharnisch@comcast.net](mailto:jpharnisch@comcast.net)  
Public Health Nurse – Chinh Tran, RN  
email: [tranc@uw.edu](mailto:tranc@uw.edu)  
Telephone: (206) 744-5113

### **SPRINGDALE HD CLINIC**

Joseph H. Bates Outreach Clinic of Washington  
County  
614 E. Emma Avenue, Suite 247  
Springdale, AR 72764  
PH: (479) 751-3630 Fax: (479) 751-4838  
Physician: Linda McGhee, MD  
email: [mcghee@umas.edu](mailto:mcghee@umas.edu)  
Public Health Nurse - Pansy James, RN, Clinic  
Administrator  
email: [pansy.james@arkansas.gov](mailto:pansy.james@arkansas.gov)  
Telephone: (479) 435-4614

### **TEXAS HD CLINICS Headquarters**

Department of State Health Services  
Hansen Disease Program  
P. O. Box 149347, Mail Code 1939  
Austin, TX 78714-9347  
PH: (800) 252-8239  
Fax: (512) 365-7824  
Nurse Consultant: Elizabeth Foy, RN, BSN  
email: [elizabeth.foy@dshs.state.tx.us](mailto:elizabeth.foy@dshs.state.tx.us)  
Telephone: (512) 533-3144

### **Denton County Public Health**

Denton Office  
535 S. Loop 288, Ste. 1003  
Denton, TX 76205  
PH: (940) 349-2900  
Fax: (877) 865-2587  
Primary Physician – Dr. Javed Akram  
email: [Javed.Akram@dentoncounty.com](mailto:Javed.Akram@dentoncounty.com)  
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Primary Physician - Dr. Adriana Vasquez  
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# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

## GET TO KNOW THE FORTY & EIGHT

The **Forty & Eight**, an honor society of veterans created in 1920 and **The STAR's** primary funding organization, draws its origin from World War I. Millions of American soldiers in France were transported to the front in narrow French box-cars, called "Voitures," which would only hold 40 men or 8 horses. Remembering the close brotherhood of those box-car days, **La Societe des Quarante Hommes et Huit Chevaux (The Society of 40 men and 8 Horses)** was formed and local Voitures began organizing as outstanding Legionnaires were invited into membership. Membership is still by invitation only.

Dedicated to the needs of their fellowman, the **Forty & Eight** raises funds and support not only **The STAR**, but funds a national nursing scholarship program, various child welfare programs, provides aid to veterans and continues to promote Americanism at both local and national levels.



## FACTS ABOUT HANSEN'S DISEASE

### What is HD?

Hansen's disease, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr. Gerhard Armauer Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without difficulty and counteract most of the fears generated by the folklore surrounding this disease.

HD affects the skin, peripheral nerves, and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, and the testes.

There are both localized and disseminated forms of HD. If left untreated, HD causes nerve damage, which can result in loss of muscle control and crippling of hands and feet. Eye involvement can result in blindness.

### Where is HD Found?

In 2016 there were 216,108 new HD cases registered from 145 countries according to World Health Organization official figures. The countries with the highest number of new diagnoses are India, Brazil and Indonesia followed by some of the African nations. More than half of all new cases of leprosy are diagnosed in India.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began who are still living. This includes approximately 3,300 cases currently receiving medical treatment for HD by the NHDP Ambulatory Care Program Clinics or private physicians with assistance from the NHDP. 178 new cases were reported in the U.S. in 2015. Most of the new cases were reported in Arkansas, California, Florida, Hawaii, Louisiana, New York, and Texas.

### How Does HD Spread?

While this aspect of the disease remains a medical mystery, the most commonly accepted theory is that it is transmitted by way of the respiratory tract, and abraded skin. The degree of susceptibility of the person, the extent of exposure, and environmental conditions are among factors probably of great importance in transmission. Most specialists agree that 95% or more of the world's population have a natural immunity to the disease. Persons working with HD contract the disease only rarely. Cases of HD which respond satisfactorily to treatment become noninfectious within a short time.

### How is HD Treated?

Although the sulfone drugs, introduced at Carville in 1941, continue to be an important weapon against the Hansen bacillus, Multidrug Therapy (MDT), which includes dapson, rifampin, and clofazimine, is the recommended treatment for HD in the U.S. The rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Treatment rapidly renders the disease non-communicable by killing nearly all the bacilli within a few days, although it takes a number of years for the bacilli to be cleared from the body. This slow process is what can cause a condition known as "reaction," which can cause inflammation of the peripheral nerves, leading to nerve injury, pain, loss of sensation, and muscle atrophy. If not treated promptly, this process can cause deformity and disability.

NHDP SERVICES Website: [www.hrsa.gov/hansens](http://www.hrsa.gov/hansens)