

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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The Forty & Eight –a Long Time Supporter of The Star

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Founder - Editor, 1941 - 1967

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease, 2.) Furnish vocational rehabilitation for interested patients.

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Editorial Policy On Terminology

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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Hansen's Disease in Fiji

By Erik O. Gilbertson, MD

San Diego Hansen's Disease Clinic

San Diego, CA

In July 2011, I had the pleasure of accompanying a group of colleagues from Scripps Clinic and the Loloma Foundation on a medical mission to the beautiful island of Fiji. The Loloma Foundation is a non-profit organization which has traveled and provided care and resources to the people of Fiji for over 10 years. We visited four islands/cities of Fiji during our nine-day stay. I was accompanied by Ryan, my 18-year-old son, as well as an orthopedic and plastic surgeons and nursing colleagues.

The care of Hansen's disease in Fiji is provided free of charge as part of the National Healthcare System. The entire island is only staffed by one dermatologist, Dr. Tui, as the main inpatient skin/tuberculosis facility in the city of Suva. This inpatient facility had two newly diagnosed Hansen's patients, as well as other patients with dermatologic conditions requiring hospitalizations such as extensive psoriasis. This clinic follows the standard W.H.O. protocols and has routine inpatient overnight facilities and around-the-clock nursing and wound care staff. Hansen's disease is a recognized disorder and is not uncommon in this tropical island chain.

During my stay on the main island of Suva, I was fortunate enough to be able to lecture to several different groups not only regarding the National Hansen's Disease Program and our clinic in San Diego, as well other dermatologic topics such as melanoma, eczema, et. cetera. I lectured to the graduate students of the Fiji Public School of Health and Internal Medicine/Hospitalist Program at the main hospital at the Colonial War Memorial Hospital. We also traveled to Labasa Hospital on the other large island of Vanue Levua and conducted two different dermatology clinics and gave lectures to the internal medicine and family practice residents regarding Hansen's disease and other dermatologic diagnosis.

Our last final days were spent at the beautiful island of Tavenui Island, a small island with one hospital, two physicians. The main Fijian dermatologist, Dr. Tui, is at this facility again once every two months for clinics. We had a busy clinic and saw over 30 patients in one morning and were able to disseminate information to the hospital staff, nurses, physicians, and residents regarding the diagnosis and treatment of Hansen's disease and their dermatological disorders.

As a whole, it was an excellent experience, not only for myself, my colleagues, and children, but also was an ability to learn about Hansen's disease from a different perspective. I can now better appreciate how another culture recognizes this disorder and promotes its treatment and acceptance. We hope to return at some point in the future to help better the healthcare of Fiji.

Ten Practices for Overcoming Stigma

By José Ramirez Jr.

I. Thou shall be forbidden to label anyone.

II. Thou shall be forbidden to reject anyone with different abilities.

III. Thou shall not fear someone simply because they are different.

IV. Thou shall embrace the U.N. Article I, Declaration of Human Rights.

V. Thou shall refer to a person with different abilities using person first language.

VI. Thou shall work to eliminate the negative effects of stigma on others.

VII. Thou shall educate others about stigma.

VIII. Thou shall advocate on behalf of others.

IX. Thou shall work to overturn the Law of Silence.

X. Thou shall strive for inclusion.

National Hansen's Disease Programs (NHDP) Residents Content with New Home

By Mary Dudley, R.N., Director of Nursing, NHDP

Almost two years have passed since former Carville residents under the charge of the National Hansen's Disease Program (NHDP) were relocated from the third floor of Ochsner Hospital in Baton Rouge to their new home across town at the Saint Clare Manor (SCM) Nursing Home.

The residents, in their 70's and 80's, quickly accepted their transition. On the first day they arrived, they rolled around in their electric wheelchairs familiarizing themselves with the facilities and all seven halls of SCM. Our residents enjoy the comradery of being together on one hall, fondly referred to as the 200 Hall. In this setting they can maintain that sense of community they have come to know, which sustains their decades long relationships. This setting continues to allow them to communicate in a common language and enables them to be watchful over each other and thus embrace the changes in life they face together. But they clearly enjoy making new friends with the hundreds of residents they mingle with daily from varied areas throughout the nursing home.

The residents attend religious services from various denominations on a daily basis, with more formalized services occurring on Sundays. They enjoy and participate in festive events such as Mardi Gras Parades, mock weddings, fashion shows, luaus, daily bingo, bowling, gardening clubs, auctions, monthly birthday parties, and seasonal parties which occur on holidays such as the Fourth of July, Veteran's Day, Christmas, etc. Some of our residents are active members of the SCM Resident's Council. The purpose of the council is to provide feedback to the nursing home administration regarding how life can be enhanced in their environment.

As with any change, there are obstacles which must be overcome. The two greatest challenges for the residents were in the areas of food and transportation. Residents were accustomed to having greater variation in their selection of food choices with regard to ethnic choices, while residing at Carville and Ochsner Hospital. Food choices in a long-term care facility are more restricted and there is limited opportunity to make changes if one is not happy with the "menu of the day". Residents have learned to overcome this change by having a moderate food store in their room. In addition, they continue to enjoy restaurant outings on a regular basis which are sponsored in conjunction with the NHDP Activity Department.

Transportation to and from medical appointments is the second area where residents experienced a significant change from their former life. In the new system, medical appointments are made for residents and transportation to and from that appointment are scheduled with a medical transportation vendor. The medical transportation system picks up numerous residents from various health care facilities and delivers them to their appointment based on time of appointment and proximity of the facility. This means the NHDP residents now travel with unfamiliar people and go to numerous locations before reaching their personal destinations. An attendant from the nursing home always accompanies the resident to medical appointments. Once the medical appointment is completed, this process is reversed until the resident returns to the nursing home. The NHDP residents were accustomed to being transported directly to their appointments and back to their place of residency immediately following the appointment. On the positive side these more prolonged trips present the opportunity to meet new friends and see different parts of the city.

Despite food and transportation issues, residents are adjusting well to this transition in the cycle of life. Much of the success of this transition can be attributed to the resilience of the residents, the consistent, caring staff on the 200 Hall, and a supportive and cooperative relationship between Saint Clare Manor and NHDP's administrators, physicians, nurses, therapists, interpreters, and other personnel. Our residents are happy in their new home and most are very optimistic about whatever challenges lie ahead of them.

I Remember When...

By Simeon Peterson as told to Elizabeth Schexnyder

When I first got to the Carville Hospital The Star was downstairs in House 15 and Stanley Stein was the editor—that was in 1951.

Anne Page worked at The Star as well as her husband Hank Simon. I don't remember what Hank did—maybe a manager of sorts. Anne worked closely with Stanley Stein. She often wrote a column. Anne and Hank had a cottage on the backside of the hospital—in an area called Cottage Grove. Mary Ruth worked in The Star offices too. Her husband Daryl ran the Post Office for the patients in the Rec Center. Max Gonzales translated articles from Spanish to English. Claude Triche took care of the mechanical repairs of the presses. Ray Elwood worked there too; he was really young when he started. After Emmanuel Faria arrived from British Guyana, he began reporting for The Star very quickly. He got here right after Stanley Stein died. That was especially sad for him because Stanley Stein was his hero. Emmanuel first read The Star as a young man in a leprosy hospital in South America. It made him want to come to Carville.

One of my countrymen from the Virgin Islands worked at The Star, Charles Bennison. He was a US veteran of WWII, a very smart man. He went to Catholic School where he



Pressroom, The STAR, Carville, 1950's. National Hansen's Disease Museum Collection.

learned how to type and take shorthand. He ran the presses for The Star after he arrived in 1951. Charles ended up going through the hole in the fence after Dr. Gordon took over the hospital in 1953. I'll come back to that.

When The Star threw a party, they threw it for everyone. The biggest one was at Christmas. The Rec Hall was covered with lots of decorations. The Star worked hard to get everything ready for the party, there must have been a dozen patients working there in the 1950s.

I wasn't involved much until The Star moved to Bldg. 27, in the early 1960s I think. The print room was downstairs. I helped transport the fresh copies of The Star from the presses to the of-

fices where they were labeled and tied up to

be shipped out. One time I was too efficient and was outpacing the printing presses and the guys in the print shop shouted "Whoa, slow down! You're making us look bad!" There were thousands of copies getting ready to be shipped all over the world.

After Stanley Stein died in 1968, Louis Boudreaux took over. Because Louis lived in his own private cottage "in the back" he took his meals there too, so I never got to know him. He was a hard worker; unless he was working at The Star I didn't see him around much. When he wasn't working he was home with his wife Kitty in Cottage Grove. The first time I saw The Star magazine was in St. Croix. Beryl Clarke, she was a patient in the St. Croix leprosy hospital – she used to subscribe to The Star and she would read it to us. Beryl focused on the articles about the medical and surgical advances. That was back in the 1940s. She helped us to write letters to Stanley



Pressroom, The STAR, 1940's. National Hansen's Disease Museum Collection



Setting linotype, The STAR, Carville 1950's. National Hansen's Disease Museum Collection

Stein. By 1944, Beryl had written so many letters to Stanley that he had pestered the Medical Officer in Charge of Carville, Dr. Guy Faget, to visit us in the Virgin Islands. Dr. Faget addressed the patients after he arrived, actually discouraging us from relocating to Carville. After Dr. Faget died in 1947, Dr. Frederic Johansen became the next Medical Officer in Charge. He, along with Governor Hastings (who was appointed by the US President) addressed the patients in St. Croix, saying that if the patients from the Virgin Islands wanted to come to Carville, they were free to do that. Nineteen or twenty patients decided to make the trip in 1951. In 1952, 6 or 8 more Virgin Island patients joined us in Carville. Carville was different. But I got used to it.

Beryl didn't want to come to Carville though. Her family owned a large plantation on St. Croix. Her brothers, Charlie and Dennis, worked on their father's plantation. In the 1940s, her family used to run a transportation shuttle to and from Christiansted and Fredericksted, the hospital was the last stop on the line – that's how families came to visit. The bus ran every day. Patients could not ride of course. In the earlier days the bus never entered the hospital compound. There was a bus stop of sorts where the visitors could wait next to a fence for the patients to meet them. They could never get any closer to each other than the other side of the chain link fence. Later on the hospital built an inside visitors station where family, friends and patients could sit together.

Actually there was a lot of commodity exchange that happened right there inside the new visitors station. Every Friday the hospital doled out codfish, onions, sardines, cornmeal and other commodities to patients. There was also staff who cooked for the patients daily, so we would save the groceries and secretly pass it to our visiting family. The matron on duty knew we were doing this but she turned a blind eye. She was pretty nice. I didn't see Beryl again until 1968 when I visited my old home in the Virgin Islands. She was living in a house that her father built for her on his plantation. I also went back to the site of the old hospital to look around; it was fixed up as a housing project by then. There were no more fences. The old distillery next door that made rum and all kinds of awful smells was now a cement plant. The Catholic chapel was still standing. The most surprising thing was nearby there was a new super market within walking distance to where I spent so much time near the edge of the hospital grounds.



Kitchen in Leprosy Hospital, Christiansted, St. Croix, Virgin Islands, 1941. Library of Congress LC-USF34-046992-D.



Unidentified woman from Leprosy Hospital, Christiansted, St. Croix, Virgin Islands, 1941. Library of Congress LC-SF34-046907-D.

After Dr. Johansen retired in 1953, he was replaced by Dr. Gordon. Dr. Gordon didn't get off on a good foot with Carville patients. He told those of us who had come from the Virgin Islands a couple of years earlier that we had received all the medical care that Carville could give, so we should go home.

We figured that the doctors here at Carville and the Governor of the Virgin Islands had made a deal to treat us and then send us home. The Virgin Island patients weren't told this, only the part that they could come to Carville to get the best medical treatment and stay if we wanted to. That's when Charles Bennison and 18 other Virgin Islanders went through the hole in the fence to New York. Me and a couple of others from the Virgin Island didn't go because we were still having surgeries. Dr. Gordon was something. He wanted all the patients to wear hospital clothes or pajamas. He said "you're in a hospital, you aren't going anywhere". It took all of Stanley Stein's political connections and 5 years of campaigning in The Star, but we were rid of Dr. Gordon by 1957. And I'm still here.

Louis Boudreaux: He Filled Stein's Shoes

Looking back at the Editors of The Star through the eyes of Julia and Ray Elwood

Julia:

Louis Boudreaux was the name of The Star's second editor and the alias he took when he was admitted to the United States Marine Hospital #66 in the 1930's. With Stanley Stein as his predecessor Louis had "big shoes to fill."

Born Louis Anthony Houillon in Donaldsonville, Louisiana, "Louie," as his friends called him, was diagnosed with leprosy in his late teens while he attended school at a seminary. This prospective priest was shocked when he learned that his desk and school books had been burned after the school was informed of his diagnosis. He was sent to the Carville hospital and while there he found his brother who had been previously diagnosed.

After some adjustment to his new life and routine at Carville, Louie began to make friends and joined the activities provided by the Recreation Department. It was during that time that he met a diminutive redhead beauty from Texas who stole his heart. They wanted to get married, but the set of laws that existed at this institution dictated that patients could not marry each other. Determined to be happy as a married couple they decided to escape through "the hole in the fence" long enough to be married by a priest who lived nearby. They returned to Carville as man and wife.

In the back part of the main complex there were "shacks" made of leftover lumber built by patients. They named this area "White City." These groups of houses were constructed as an attempt by patients to live a "more normal life" They furnished and made them livable. All the houses were painted white, hence the name. Even though these houses were on hospital grounds, they were geographically separated and this gave the patients a feeling of detachment from institutional living. Louie and Kitty acquired one of these homes. From the very beginning their house was always open to all their friends.

Ray:

Louie started his work at The Star in September of 1958 as a staff writer. He titled his column 'Lou's Views.' Louis was a writer until January 1964 when the late Stanley Stein, founder and editor, made him managing editor. Upon Stein's death in 1967 Louis formed an Editorial Board becoming its first chairman.

Louis did an outstanding job as chairman of the board. Under his leadership, The Star grew from 24,000 subscribers (at the time of Stein's death) to 86,000 in 1986. In addition to the regular subscribers in the U.S. The Star had reached 150 foreign countries. Much of this was accomplished with the help of the National Forty & Eight, a veterans' organization who adopted The Star Magazine as a national project and to promote subscriptions.

One would think that a man who was blind would be limited, but not Louis Boudreaux. For many years he was a leader in the community serving on the board of the Patients' Federation. He was a charter member of the Point Clair Lions Club and served as secretary until his eyes became a problem. He remained active in the club for many years.

After his beloved wife Kitty died, The Star, which before was merely a job became Louie's life. The last 15 years of his life were dedicated to his dream that someday, Hansen's disease would be treated as any other chronic illness without the stigma attached to it.

As a close friend of Louie's, I am fortunate to have been a part of his life and even more fortunate to have been able to work with such an extraordinary man.

In an article which appeared in The Star Magazine of May-June 1986, Dr. John R Trautman, Assistant Surgeon General, who served as Director of the National Hansen's Disease Center for more than 28 years wrote the following about Boudreaux:

"Until 1966, my association with Stanley Stein was closer than with Louis Boudreaux, primarily because Stanley was one of my patients and he was by then a legend. But certainly, I also knew Louis quite well and was impressed with his work, as obviously was Stanley. Louis's rise to the top after Stanley died was due in large part to the confidence in, and respect for Louis by Stanley and the other members of The Star staff."

Thus, when I returned to Carville in January 1968, Louis Boudreaux was Chairman of the Editorial Board of The Star. I simply knew him as the Editor. Many thought that The Star might crumble after Stanley Stein died. But those predictors of doom didn't know the caliber of the man known as Louis Boudreaux and the staff he headed. Nor did they count on the tremendous support given by the members of the Forty and Eight veterans organization."

Certainly Louis was an inspiration to me. What he did, over such a long period of time, and under such challenges was incredible. He was not only blind, but his hands were affected by the disease and he was in almost constant pain from other conditions. Furthermore, he had no sensation on his skin. In fact, I heard him say in public that the only way he could test the temperature of water or food was with his tongue, which did retain its sensitivity. Being blind is difficult, but being blind and having no sensation, coupled with everything else, seemed to create barriers which no one could successfully overcome. ...but Louis did overcome them.

I regarded Louis as a true friend and colleague for whom I had great respect and one who had a definite impact on my thinking.

It is our opinion that Louis Boudreaux successfully and gracefully filled the shoes of the former Founder-Editor, Stanley Stein.

COUSINS

By: Lorenzo DeStefano

I was thirty-seven before I learned I had a relative with Hansen's disease. My mother, Lydia Marie Silva, was born in 1922 on the island of Kaua'i to Portuguese immigrant parents from the Azores. Like her cousin, Olivia Robello, she grew up in a tight-knit, hardworking community where family pride and the magnetic pull of assimilation often clashed. People kept anything potentially embarrassing locked tightly in the closet. If word got out that someone in the family had contracted such a dreaded disease it could have negative effects on their social standing and, in many cases, the way they were treated at work, at school, and even in church.

Although I was born and raised in Hawai'i, I didn't meet Olivia in Kalaupapa until 1989. By then the antiquated rules surrounding "the separation sickness" had largely vanished, though it is interesting to note that the Department of Health for the State of Hawaii still administers services to leprosy patients through its "Communicable Disease Division".

In the sixteen years that we were able to share together, Olivia taught me more about humanity than I could have ever gotten from a University degree in the subject. She was a living witness to the wrenching public policy decisions that forever altered people's lives and brought them to a place from which few ever expected to emerge. It was through Olivia that I began to appreciate the feelings of people who were used to being disdained, avoided, and scorned as "lepers".

Olivia and thousands of others have struggled all their lives against the centuries of stigma and fear which this word has caused. Like so many other hurtful and now-outdated terms used to label people by their color, religion, sexual orientation, or, in this case, their medical condition, "leper" perpetuates harmful stereotypes and robs people of their rights as individuals.

Every time I hear this word, and I've heard it quite a lot since being sensitized to it by Olivia and others, I can feel the pain she felt when she heard it used on the television show "Mash" in the 1980s. When her letter to Alan Alda went unanswered she decided to write "*Olivia-My Life of Exile in Kalaupapa*". Available from Pacific Historic Parks (<http://www.pacifichistoricparksbookstore.org/browse.cfm/4,44.htm>), her book chronicles her nearly 70 years of life on the remote peninsula. Her devotion to the memory of the Catholic priest Father Damien and for the nun Mother Marianne Cope, who selflessly ministered to patients in the early days of the settlement, helped form Olivia's own activist streak as she continued to fight for the rights of people suffering from this long-misunderstood condition.

Anwei Law, international coordinator of IDEA (Integration, Dignity and Economic Advancement), an advocacy and support organization for people with Hansen's disease, knew Olivia well and has worked for years to help dispel historical inaccuracies related to the condition. *"She was very opposed to the word 'leper.' ... She wanted people to know her as Olivia, for people to see her for who she was and not the disease she had."*

While I realize that this word, like many others, may never completely disappear from use, it is still important to remember the responsibility we all have to accurately comprehend the historical attitudes that have caused words like "leper" to be used in common parlance for far too long. We should learn from the experiences of these brave people, living and dead, and celebrate them as individuals who tried their best to rise above the adversities they suffered as societal outcasts in order to live their lives with quiet dignity.

Lorenzo DeStefano
Ventura, Ca.



Cousins Lorenzo DeStefano and Olivia Robellow Breitha(1916-2006) in the kitchen of her Kalaupapa Home.

TRAINING OF WHO PROGRAM MANAGERS

By: Jose' Ramirez, Jr., LCSW, Cairo, Egypt

During the summer of 2010, the World Health Organization (WHO) hosted a meeting in Manila, Philippines in order to finalize guidelines designed to better empower persons affected by leprosy. The participants included WHO Program Managers, stakeholders who are involved in research and advocacy and persons affected by leprosy from 15 different countries. The guidelines were refined and adopted by WHO in 2011.

The guidelines, in order to ensure implementation at the local level, are written in a simple and concrete fashion and are being translated into multiple languages. A training session was held in New Delhi, India in September with attendees from the WHO Asian Region. Dr. G. P. Gopal represented persons affected by leprosy.

On November 16 – 17, 2011, another training for the WHO Eastern Mediterranean Region (EMR) was held in Cairo, Egypt. Jose' Ramirez, Jr. represented persons affected by leprosy and his travel was sponsored by WHO and The American Leprosy Mission (ALM). The meeting included a discussion on Guidelines for Global Surveillance of Drug Resistance in Leprosy and Guidelines for strengthening participation of persons affected by leprosy in leprosy services.

Attendees at the meeting were national health care administrators responsible for diseases such as HIV-AIDS, TB and Hansen's disease. Some of the administrators were new to the world of leprosy. Countries represented included: Afghanistan, Djibouti, Egypt, Iran, Iraq, Lebanon, Libya, Morocco, Oman, Pakistan, Saudi Arabia, Somalia, Sudan, South Sudan, Syria, Tunisia, and Yemen.

The program was comprised of five parts. The **first** was a review of existing data on cases and Grade-2-disabilities (visible) based on the WHO June, 2011 issues of the Weekly Epidemiological Record. Based on the data, it appears that there are some inconsistencies on the data related to the number of new cases. The **second** was updates from each country on diagnosis, treatment and challenges. The country representatives reported that stigma was very high and thus a contributing factor to G-2 disabilities. **Third** was a presentation by Ramirez titled "Guidelines for Ownership: A Process that Becomes an Event." This was followed by Professor Cairns Smith, from the University of Aberdeen in Scotland, on strategies and critical review of G-2 disabilities. Both presentations were followed by group work sessions designed to address questions related to enhanced participation and consistent reporting methods. **Fourth** was an intense discussion on all of the content presented and **fifth** was conclusion and recommendations. Based on the discussions and data reviewed it appears that there might be human rights violations in some countries when immigrants have been deported as soon as diagnosed with HD.

The WHO goal was to decrease G-2 disabilities by 2015 was discussed, with an emphasis on a standardized and accurate system of reporting cases, collection of data, level of training (clinical skills), and early diagnosis to prevent G-2 disabilities by initiating a myth-busting strategy of educating their respective religious leaders. By lessening the stigma of leprosy, persons who suspect they might have the illness will be more receptive to seeking medical treatment early and thus prevent G-2 disabilities.

The participants agreed that stigma was deemed high in each of the countries represented at the meeting, and this contributes to the delay in persons seeking medical treatment and rehabilitative services. Uniformly they agreed that stigma can be lessened with the implementation of the Guidelines for strengthening participation of persons affected by leprosy in leprosy services. WHO has made a commitment to have the guidelines presented by Ramirez implemented at each of the regions (EMR, Western Pacific Region, Americas Region, African Region and Asian Region). Their level of implementation will be presented at their annual regional meetings. Each of the participants was provided with a copy of "Ten Practices for Overcoming Stigma" included in this issue.

Hansen's Disease Workshop for Pacific Island Healthcare Workers

The National Hansen's Disease Programs sponsored a Workshop on Hansen's Disease for physicians and nurses from the Federated States of Micronesia (FSM) and the Republic of the Marshall Islands (RMI), from Sept 6-9, 2011, at its headquarters in Baton Rouge, LA. Attendees, selected by the Ministry of Health of each country, included four physicians from the FSM, and one physician and three Public Health nurses from RMI. In addition, one State Public Health nurse and two Marshallese community outreach workers from Springdale, Arkansas attended. This community in NW AR is comprised of a large number of migrants from RMI with a high prevalence of HD. In selected sessions, participants were teleconferenced in from the CDC Special Bacterial Pathogens Branch in Atlanta, the HHS Region IX office in Honolulu, and from Hawaii's Hansen's Disease Program in Honolulu. Each morning and afternoon session focused on one topic related to a specific medical or public health aspect of HD, concentrating on 1) awareness of the early signs of this disease so that individuals can be referred to a doctor for diagnosis, and 2) identifying local issues that delay or interfere with the diagnosis and treatment of this disease, and 3) the importance of maintaining long-term treatment once the diagnosis has been made. Participants were asked to distill their conclusions for each session to short 'bullet points' for a poster designed to assist in educating additional health workers in their own countries. The posters were prepared electronically, and the final 24" x 36" posters were printed out on the last day for each participant to take home with them. Subsequently, these training posters have been translated into languages of the RMI and FSM, respectively.

The outcome of this meeting and training will be an increase in early diagnosis of HD in Micronesia and the Marshall Islands, which, coupled with implementation of the World Health Organization's multiple drug therapy regimen, should slow or prevent the trajectory of disability and deformity associated with untreated advanced HD. Moreover, as migrants from the FSM and RMI can freely relocate to the U.S., heads up information provided to the NHDP should provide continuity of care for their disease when they are in the U.S.



Examples of Efforts to Educate

by Jose' Ramirez, Jr.

The Star will start a new section on how individuals have contributed to the education of others on Hansen's disease and thus dispelling myths. READERS ARE ENCOURAGED TO SUBMIT THEIR OWN PERSONAL EXAMPLES FOR PUBLICATION IN THE STAR.

On September 30, 2011, Jose' Ramirez, Jr. made a presentation at the University of Texas at Houston School of Medicine titled "The Dynamics of Stigma Across Cultures." The audience was introduced to the concept of always utilizing person first language such as "the person affected by leprosy," instead of linking the individual to the disease in a negative manner as is often referenced in biblical terminology. Those in attendance were strongly urged to avoid labeling across cultures. Labeling only adds fuel to stigma.

On October 19, 2011, Ramirez presented at the American College of Acupuncture and Oriental Medicine on "Stigma and Cultural Issues" in Houston, Texas. The students were provided with numerous examples of how persons from different cultures using a variety of languages can become loyal patrons of their business. This can only be accomplished via the understanding of differences and avoidance of stigma producing stares, actions and comments. The stigma associated with Hansen's disease was used as a unique example of how human beings do not seek much needed services due to evidence of rejection or fear.

On November 9, 2011, Ramirez presented on "The Dynamics of Stigma in the World of Leprosy." Over 200 nurses from the combined county and city health department in Houston, Texas were provided with information on the history of stigma, the impact of stigma and how the medical profession can help in reducing stigma. Considering that those in attendance deal with services for person with TB, HIV-AIDS and other illness, they were surprised to learn that HD is only "mildly communicable."

On December 13, 2011, Dr. Paul Johansen of Pittsfield, Massachusetts sent the following letter to the producers of a film which perpetuates the myths of leprosy. Dr. Johansen has been a long time advocate on behalf of persons affected by leprosy.

Dear Nick Park and Aardman Animations: <http://en.wikipedia.org/wiki/NickPark>

I love your Wallace and Gromit movies and was particularly impressed by Creature Comforts. So it was especially upsetting for me to see the trailer to "The Pirates! Band of Misfits" in which a sailor claims to be aboard a "leper ship" just before his arm falls off. For starters, the term "leper" is anathema to those with the disease.

I have spent over 20 years educating people on the harsh reality of leprosy stigma and how life-threatening it can be for people who have this disease. I am gravely concerned that your movie will undermine the efforts of organizations like IDEA (International Association for Integration Dignity and Economic Advancement www.idealeprosydignity.org) to assist people with Hansen's disease live normal lives.

I encourage you to modify your trailer and movie to be sensitive to this very real problem.

Sincerely;

Paul Johansen

A follow up email was sent by Ramirez to the producers of "The Pirates! Band of Misfits" and a request to First Lady Obama that this movie not be shown at the White House.

The purpose of this communication is to let you know that your movie, "The Pirates! Band of Misfits" will push the myths of Hansen's Disease, more commonly known as leprosy, on to a new generation of children. I simply do not understand why you find the perpetuation of myths and labels related to leprosy such a funny topic. Children learn from adults and you are not a good role model in producing positive outcomes.

My reaction to your negative portrayal of persons affected by leprosy is not only based on a personal impact (diagnosed and placed at the national leprosarium in Louisiana for seven years), but also on a professional level (work with persons with mental and cognitive disabilities and serve as consultant on stigma to the World Health Organization). Regrettably, your movie will soon undo all of the hard work I and others have been doing for decades teaching children that it is not OK to label, reject or fear those with different illnesses, such as leprosy.

Hopefully you and your publicist will immediately commence educating children that leprosy is curable, the illness does exist in the U.S, body parts do not fall off, and persons affected by HD are not misfits, pariahs or "lepers" (a horrible word that is always defined negatively and spells repel in reverse).

Dear First Lady Obama,

Happy holidays to you and your family.

The purpose of this letter is to strongly urge you to not allow the showing of the movie, "The Pirates! Band of Misfits" at the White House. The reason for my request is that the movie perpetuates a very negative image to children of those of us affected by leprosy. Since my diagnosis of Hansen's disease, more commonly known as leprosy, and hospitalization for seven years at the national leprosarium in Carville, LA., I have attempted to dispel myths about my millions of brothers and sisters throughout the world, including the U.S. This movie causes grave damage to our efforts to educate and to be accepted as human beings.

Please consider my request. The attached copy of an email sent to the producers further explains my concerns.

Citizen-Soldier by Robert Williams*

This is the story of a citizen-soldier. He was not a decorated “hero”, he did not have banquets held in his honor upon his return from war, and his name is not in any history books. When George Williams returned home from France in the early months of 1919, he did what generations of citizen-soldiers did before him. He returned to his family, picked up his life, and moved forward.

I only knew my Grandfather for a short while; he died when I was only seven. He never talked about his war experiences or his time in France. Like many men of his generation, he did not like to talk about himself or his exploits. The only way I knew he had even been in the Army and served in France in World War I was through the stories told by my Uncle, who did think of his Father as a hero and wanted the members of my generation the family to know what he had sacrificed for us before we were even born. My memories of my Grandfather are of a very tall (to a six-year-old boy), slightly stooped man who always had a smile on his face and a piece of hard candy hidden away in his jacket pocket. He also had the magical ability to find that dime or quarter that had somehow found its way behind your ear. He did not look like what I thought of as a warrior and he certainly did not portray himself as one.

After George answered his Country’s call and, happily for his descendants, returned home to his wife and young son, he continued to serve his community. He became a police officer in Washington, D.C., and walked a beat until he retired in the early 1950s. He and my Grandmother had three more children, including my father, and went about the task of raising them. He did what millions of other American citizen-soldiers have done since the end of the American Revolution. He came home, put his war experiences behind him, and got on with his life.

Maybe that is the real story here. My family, like countless others, has had soldiers and sailors serve in almost every war this Country has fought. When their service ended, they came home and returned to their communities to live their lives in peace. My Grandfather, George Williams, was just one more man in that long line of men and women. And maybe that is the real strength of this

Country and its people. An unbroken line of men and women willing to serve and sacrifice for those of us who hadn’t even been born.

**Robert Williams is a professional colleague and friend of Jose’ Ramirez, Jr. in Houston, Texas. He recalled that his “hero” of WWI was once a member of the Forty and Eight.*

***** ATTENTION *****

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Changing Of The Guard

by Jose' Ramirez, Jr.

The Forty & Eight has seen many changes at The Star because they have been part of these changes via their generous support of the publication.

Similarly, the Forty & Eight undergoes a transformation every year at the annual conference. In September, members of the organization met in Vancouver to elect new leadership.

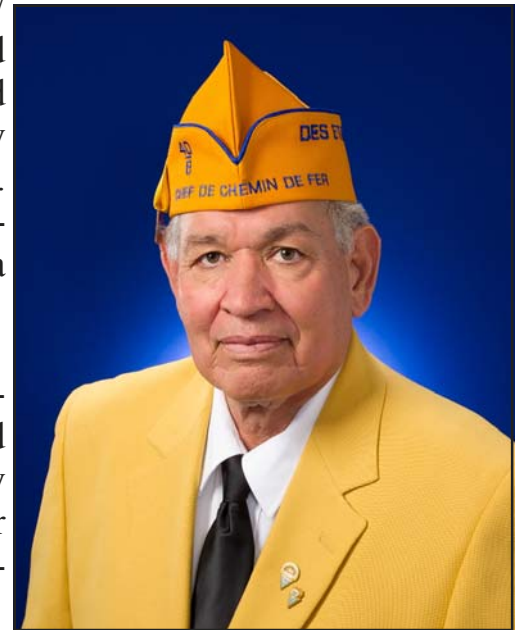


During the past year, Forty & Eight has been led by **Henry E. "Hank" Kwiatkowski** as Chef de Chemin de Fer. Hank, being a resident of Lake Bistineau near Doyline, LA is no stranger to The Star as he has visited the national leprosarium, now the Louisiana National Guard Training Facility, numerous times.

Hank has been a member of The Forty & Eight for 23 years and has served on many local, state and national positions before elected to its highest rank. After discharge as Captain in the U.S. Army/Airborne, he worked in the aerospace and manufacturing industry. Later he founded his own automotive business and eventually retired to spend time with his wife, Sharon. They have two children and three grandchildren. The Star is proud to have Hank as a

friend.

At the Vancouver conference, in September 2011, The Forty & Eight members elected **Robert "Bob" Molina** as their new leader. Bob has described his elections as a "dream come true." He too has been a visitor to the facility and Hansen's disease museum at Carville, Louisiana. His chosen motto for this year as "YES WE CAN." He hopes to increase Forty & Eight membership as they "make up the greatest veterans in the free world."



Bob served in the U. S. Army and has held many positions of prominence. These include Chef De Gare, Aide de Camp Nationale, Sous Chem de Chemin de Fer and Amerianism Directeur Nationale.

Señor Molina was born and raised in Tucson, Arizona and currently lives in Corona, Arizona with his wife Becky. The Molinas have six children, 13 grand children and four great grandchildren. Welcome aboard Chef de Chemin De Fer Molina.

The Forty & Eight is supported by the women of La Societe de Femme. The Nationale **La Presidente for 2011 was Pat Jones and La Presidente for 2012 is Sandy Woods.**

La Presidente Passe Jones, born and raised in Delaware and current resident of Florida, promoted La Societe de Femme during her term and adopted the program “Pennies for POW,” presenting a check for \$2,019.63 to the 40 & 8 at Nationale in Vancouver. Due to her success with this program she was appointed Nationale POW Chairman for 2012.



La Presidente Nationale Passe Jones learned to be a leader by having three careers: housewife (she and husband Roland raised four children – one deceased, and have eight grandchildren and three great grandchildren; professional (has worked for various companies); and volunteer (American Legion Auxillary Unit 38 and La Societe de Femme). She enjoys entertaining her family by singing karaoke. A visitor to the Carville facility several times, she has been a great friend to The Star.

Another wonderful friend to The Star is **Sandy Wood, the 2012 Nationale La Presidente**. At her swearing in on

September 17, 2011, La Presidente Woods thanked many of the special Dames. They have provided her with guidance, advice and support, including her valued friend and mentor Dame Pat Jones. La Presidente Woods has chosen her theme as S*T*A*R*, an Acronym for Strength Through Active Recruiting. Her special program is the Carville Museum Fund.



La Presidente Nationale Wood was raised in Randolph, MN and currently lives in Richmond, VA with her husband Mike. Some of her unique accomplishments have included: working for the same employer for 38 years; holding many positions in the Grande de Virginia, and awarded the Virginia Grande Dame of the Year in 2007; and assisting five different La Presidente Nationale to lay a wreath at the Tomb of the Unknown Soldier at Arlington National Cemetery on Memorial Day.



Finally, **George Henry Willis** has relinquished his position of **Carville Star Directeur** to **Joe Steil**. Directeur Steil is a native of New Mexico, raised in Iowa and now resides in Noble, OK with his wife Trina. They have one son and one daughter. He retired from the Air Force with the rank of Major. He now specializes in making custom golf clubs, serving on several boards which render services to children with disabilities and volunteers on many 40 & 8 projects.

The Star Editorial Board and the magazine readers welcome Presidente Molina, La Presidente Wood and Directeur Steil to the Carville family.

HANSEN'S DISEASE CLINICS

ATLANTA HD CLINIC

Emory MidTown Hospital
550 Peachtree Street NE
7th Floor MOT
Atlanta, GA 30308
PH: (404) 686-5885 Fax: (404) 686-4508

Primary Physician – Dr. Phyllis Kozarsky
email: phylliskozarsky@emoryhealthcare.org
PH: (404) 686-5885

Public Health Nurse: Roberta Dismukes, RN
email: roberta.dismukes@emoryhealthcare.org
PH: (404)-320-6662 PH: (404) 686-7668

BOSTON HD CLINIC

Lahey Medical Center
41 Mall Road
Burlington, MA 01805
PH: (781) 744-5670 Fax: (781) 744-5687
Primary Physician - Dr. Samuel Moschella
email: samuel.l.moschella@lahey.org

Public Health Nurse
- Ms. Stephanie Burns, RN, D.N.C. *email: stephanie.a.burns@lahey.org*
After Hours: (781) 744-8445

CHICAGO HD CLINIC

University of Illinois
College of Medicine at Chicago
Department of Dermatology, (MC 624)
808 S. Wood, RM 376 CME
Chicago, IL 60612
PH: (312) 996-0734 Fax: (312) 355-0870

Primary Physician - Dr. Carlotta Hill
email: chhill@uic.edu

Public Health Nurse – Gladys Lee, RN
email: FLLee@uic.edu

LOS ANGELES HD CLINIC

LAC+USC Medical Center
1200 N. State St.
Clinic Tower A5B123
Los Angeles, CA 90033
PH: (323) 409-5240 Fax: (323) 441-8152

Primary Physician - Dr. Maria T. Ochoa
email: mochoa@mednet.ucla.edu
PH: (323) 226-3373

Public Health Nurse - Helen Mora, RN
email: hmora@dhs.lacounty.gov

Occupational Therapist - Rob Jerskey
email: robjerskey@yahoo.com

MARTINEZ HD CLINIC

Contra Costa Regional Medical Center
Outpatient Specialty Clinic
2500 Alhambra Avenue
Martinez, CA 94553
PH: (925) 370-5868 Fax: (925) 370-5529

Primary Physician - Drs. Sutherland/Saffier
email: ssutherland@hsd.co.contra-costa.ca.us
PH: (925) 370-5867

email: ksaffier@yahoo.com
PH: (925) 370-5200 Ext.:4743

Public Health Nurse – Barbara Hobson, RN
PH: (925) 313-6757

email: Barbara.Hobson@hsd.cccounty.us

Community Health Worker - Maria Soto
email: Maria.Soto@hsd.cccounty.us

MIAMI HD CLINIC

Jackson Memorial Hospital
1611 N.W. 12th Avenue
ACC East – 2nd Floor
Department of Dermatology
Miami, FL 33136-1096
PH: (305) 585-7348 Fax: (305) 585-6397

Primary Physician - Dr. Anne Burdick
email: Aburdick@med.miami.edu

Public Health Nurse - Gail Chepenik, RN
email: gchepenik@jhsiami.org

NEW YORK HD CLINIC

Bellevue Hospital Center

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: william.levis@yahoo.com

Public Health Nurse - Lydia Macwan, RN
PH: (212) 562-6096

email: Lydia.Macwan@bellevue.nvchhc.org

Physical Therapist - Louis Iannuzzi, P.T., C.Ped.
email: Lni1@nyu.edu

PHOENIX HD CLINIC

Maricopa County Health Department
1645 East Roosevelt Street
Phoenix, Arizona 85006
PH: (602) 372-2039 Fax: (602) 372-3862

Primary Physician - Dr. Ronald Pust
Tucson Office: (520) 626-5650

Cell: (520) 668-6441
email: rpust@email.arizona.edu

Public Health Nurse - Eileen Smith, RN
PH: (602) 372-2039

email: eileensmith@mail.maricopa.gov

Physical Therapist - Tracy Carroll, MPH
email: tc Carroll@email.arizona.edu

SAN DIEGO HD CLINIC

HHS, North Central Regional Center
5055 Ruffin Road, Mail Stop: N-513
San Diego, CA 92123
PH: (858) 573-7338 Fax: (858) 573-7325

Primary Physician - Dr. Erik O. Gilbertson
email: erik.gilbertson@sdcounty.ca.gov

Public Health Nurse – Gina Sandoval, RN, PHN
email: regina.sandoval@sdcounty.ca.gov

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. Pablo Almodovar
email: dermatol.rcm@upr.edu

Public Health Nurse - Sonia Santos-Exposito, RN, BSN
PH: (787) 758-2525, Ext. 5503

email: sonia.santos@upr.edu

SEATTLE HD CLINIC

Harborview Medical Center
2 West Clinic – 359930, 325 Ninth Avenue
Seattle, WA 98104
PH: (206) 744-2128 Fax: (206) 744-5109

Primary Physician - Dr. James Harnisch
email: jpharnisch@comcast.net

Public Health Nurse – Marlene Skinnell, RN
email: mskinnel@u.washington.edu

Physical Therapist - Tom McClure, PT, CHT
email: tmcmpt@u.washington.edu

SPRINGDALE HD CLINIC

Outreach Clinic of Washington County
614 E. Emma Avenue, Suite 247
Springdale, AR 72764
PH: (479)-751-3630 Fax: (479)-973-8491

Primary Physician: Linda McGhee, MD
PH: (479)-521-0263 PH: (479) 973-8450 (office)
email: lmcghee@uams.edu

Public Health Nurse - Sandy Hainline Williams, RN
PH: (479)-751-3630 Cell: (479)-409-9134

email: sandra.hainline@arkansas.gov

TEXAS HD CLINICS

Department of State Health Services
Hansen's Disease Program
P. O. Box 149347, Mail Code 1939
Austin, TX 78714-9347

PH: (800) 252-8239 Fax: (512) 776-7787

Nurse Consultant: Linda Brown, MS, RN
PH: (512) 776-6331

email: lindaj.brown@dshs.state.tx.us
Officer Administrator: Kirbi Woods
PH: (888) 963-7111 Ext.: 6608

email: kirbi.woods@dshs.state.tx.us

Dallas County Health & Human Services
2377 N. Stemmons Freeway, Suite 522
Dallas, TX 75207-2710

PH: (214) 819-2010 Fax: (214) 819-6095
Physicians - Dr. Jack Cohen/Dr. Sharon Nations

email: jbcohendo@aol.com
PH: (817) 753-6633 (private practice)

email: sharon.nations@utsouthwestern.edu
PH: (214) 645-8800

Public Health Nurse - Nancy Bernstein, RN, BSN
email: nbernstein@dallascounty.org

Houston Hansen's Disease Clinic

Northside Health Center
8504 Schuller Street
Houston, TX 77093
PH: (832) 393-4804 Fax: (832) 393-5247

Physician - Dr. Terry Williams/Dr. Steven Mays
email: Tmwill3502@aol.com

PH: (281) 332-8571
email: Steven.Mays@uth.tmc.edu

PH: (713) 500-8329
Public Health Nurse – Marion Matsu, RN, CCM

email: Marion.Matsu@houston.tx.gov
Main: (832) 393-4798 Cell: (832) 248-7150

Texas Center for Infectious Disease

2303 S. E. Military Drive
San Antonio, TX 78223
PH: (210) 531-4526 Fax: (210) 531-4508

Physician - Dr. Robert N. Longfield
PH: (210) 531-4959

email: robert.longfield@dshs.state.tx.us
Physician - Dr. Adriana Vasquez
PH: (210) 531-4565

email: adriana.vasquez@dshs.state.tx.us
Physician - Dr. Lynn Horvath
PH: (210) 531-4524

email: lynn.horvath@dshs.state.tx.us
Public Health Nurse - Debbie Mata, RN
PH: (210) 531-4576 PH: (210) 531-4295 Cell: (210) 389-3568

Appointment Secretary (210) 531-4526
email: debbie.mata@dshs.state.tx.us

Department of State Hlth Services Region (HSR) 11

601 W. Sesame Drive
Harlingen, TX 78550
PH: (956) 423-0130 Fax: (956) 444-3295

Physician - Dr. Richard Wing
email: richard.wing@dshs.state.tx.us

Public Health Nurse – Grace Flores, RN
PH: (956) 423-0130, Ext. 5573

email: grace.flores@dshs.state.tx.us

Other Clinics

HAWAII HD CLINIC

Hawaii State Department of Health
Hansen's Disease Community Program
3650 Maunalei Avenue
Honolulu, HI 96816

PH: (808) 733-9831 Fax: (808) 733-9836
Program Manager: Lori Ching, RN

Direct Line/Voice Mail: (808) 733-4663
email: lori.ching@doh.hawaii.gov

Office Physical Address:
Diamond Head Health Center

3627 Kilauea Avenue Room 102
Honolulu, HI 96816

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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 Amaner 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 2008 the World Health Organization reported that there were 212,802 new cases of HD worldwide. In 1993, there were 591,000 new cases reported, and in 1992, 690,000 new cases. The largest numbers of Hansen's disease patients continue to be in Southeast Asia and Central Africa with smaller numbers in South and Central America. The largest number of patients in the Western Hemisphere are in Brazil.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began 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. There were 150 new cases reported to the registry in 2008. California, Hawaii, Louisiana, Florida, Massachusetts, and New York contributed the largest number of cases in 2008.

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 noncommunicable 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