

# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

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*(Cover see page 3)*

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**The Star** stands firm in its opposition to the use of the term "leprosy." We shall never abandon our campaign to secure general acceptance of "Hansen's disease." Nevertheless, the word "Leprosy" does appear in **The Star** under circumstances which we feel are unavoidable, namely: when signed articles are authored by someone who does not agree with us or when material discusses the disease prior to the introduction of the term "Hansen's disease." We dislike the word "leprosy" intensely, but we dislike the practice of censorship even more.

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## Simeon Peterson (Mr. Pete)

The 7th Editor of The Star

### Living with leprosy

Vanessa Buschsluter

BBC News Website

*Simeon Peterson, "Dr. Pete," was one of the first residents I met at Carville upon my admission in 1968. His job was to transport in wheelchairs those of us in the infirmary to appointments at the foot clinic, eye clinic, PT, OT, etc. However, he did much more, such as making new arrivals like me feel special by telling us jokes and constantly showing his friendly personality. His demeanor, snappy hats, and trademark suspenders made him a unique figure. He chose to stay "home" at Carville in 1999 when the National HD Program relocated to Baton Rouge and lives with his cat "Buddy." Currently, he is the museum "Ambassador," facility tour guide, and the sixth Editor of the 71 year old STAR. The following article is reprinted with permission from the British Broadcasting Corporation.*

*José Ramirez, Jr.  
Managing Editor*

**For almost six decades, Simeon Peterson - or Mr. Pete as he likes to be known - has called the National Leprosarium in Carville, Louisiana, home.**



He is one of the 6,500 people in the US, who suffer from leprosy or the effects of the disease.

The small, thin man, looking dapper in his black hat, shirt and braces, has braved a torrential down-pour to cycle to the former plantation mansion at the centre of the leprosarium, to tell me about his life in what until 1921 was known as the Louisiana Leper Home.

As he peels off his black wool gloves, the toll leprosy has taken on him is clearly visible. He may only have three fingers left on his right hand, but his handshake is firm.

"I was diagnosed with leprosy when I was five," he says. Then he corrects himself and says: "Hansen's Disease. I was diagnosed with Hansen's Disease."

Leprosy is a chronic infectious disease that attacks skin, peripheral nerves and mucous membranes. It is one of the most feared infectious diseases and the stigma surrounding it goes back to Biblical times. So it comes as little surprise that when Norwegian doctor Gerhard Armauer Hansen discovered the bacterium that causes leprosy (*Mycobacterium leprae*), many patients and doctors were keen to switch to its new clinical name: Hansen's Disease (HD).

Having lived with the disease for most of his life, Mr Pete is more than familiar with both terms. He tells me his brother and sister were also diagnosed with HD. Where they got it from, he does not know.

Between 150-200 people in the US are diagnosed with HD every year. But, to this day, leprosy remains one of the least understood infectious diseases.

The most commonly accepted theory is that it is transmitted through the sneezes and coughs of untreated patients, says Jim Krahenbuhl, director of the National Hansen's Disease Program. But contrary to popular belief, it is far less contagious than other infectious diseases. In fact, more than 95% of people have a natural immunity to leprosy.

Mr Pete and his siblings are among the 5% who do not have that immunity.

When he developed a spot on his finger - one of the tell-tale signs of leprosy - he went to the local hospital on his island home of St Croix on the US Virgin Islands. The hospital housed a number of leprosy patients, but offered no effective treatment.

So, when in 1951 a doctor from the only leprosarium in the continental United States came to visit and offered the patients the chance to go to Carville, he and 18 others took it.

When he arrived at the former sugar plantation on a bend of the Mississippi River, there where more than 400 patients living there. Most of them had changed their names or were using aliases so as not to cause their families any embarrassment.

Some had been taken to the leprosarium against their will, at a time when isolating patients was believed to be the best way of preventing contagion.

The severity of the leprosy cases at the hospital in Carville differed. Some patients only had small spots or lesions. In others, the leprosy bacteria had damaged the nerves in their extremities. Nerve damage meant patients would lose the sensation in their hands and feet.

Unable to feel pain, they would repeatedly injure their fingers and toes, the damaged bones would become shorter and shorter, resulting in the hallmark deformed hands and feet leprosy is so feared for.

Mr Pete has mixed memories of Carville during that time.

"It was very restrictive," he says. "We weren't allowed to leave the grounds. We had to stay here all the time."

But, he says, the wire fence surrounding the hospital was no obstacle to him and his fellow patients. At weekends, they would crawl through a hole in the fence and escape to nearby Baton Rouge to drink and dance the night away. But they always kept their identities secret.

"You couldn't tell people you were from Carville, them days you couldn't do that, they would have got scared," Mr Pete explains. "They would have said 'Oh my God, you have leprosy?' and called the police for you."

Over the decades, the rules at Carville were relaxed considerably. In 1941, 10 patients at the hospital volunteered for treatment with a drug called Promin. The results after many months of painful intravenous injections with the sulfone drug were described by doctors and patients as miraculous. It cured leprosy and within weeks it stopped patients from being contagious.

No longer contagious, the people at Carville started to be treated more like patients than prisoners. In 1946, they were given the right to vote, which had been denied to them until then. And slowly, they were allowed to leave the grounds, first on day passes, and later whenever they wanted.

Carville became its own community, and a diverse one at that, with a large number of African-American and Hispanic patients. They had their own churches, bakeries and post offices. They married and split up, organised dances, baseball games and Mardi Gras processions. But, Mr Pete says, it was not exempt from the challenges and problems of the time either, some of which he rebelled against.



"In the theatre, there were two rows of seats for us, the black. Then there were two rows of seats for the doctors - no patients could sit there," he remembers. But he and some other African-American patients started sitting there. "We're in prison already, what are you going to do?" they asked the doctors and nurses.

"And they stopped it. They may call me a rebel, but so what? You make it good for somebody else," he says and chuckles.

With effective multi-drug treatment in tablet form being developed in the 1970s, fewer and fewer patients needed to stay at the leprosarium and numbers quickly dwindled. Some elderly patients chose to move to a care home in Baton Rouge, others moved in with their relatives. But a handful decided to stay in the place that had become their home.

In 1999, the hospital relocated to Baton Rouge and Carville was taken over by the National Guard, which runs a training programme for at-risk youth. Eight former patients still live at the former leprosarium. Mr Pete says much of the community spirit has disappeared, though. The patients do not get together like they used to. "After supper, everybody goes into their rooms and switches on their TV. I'm telling you that TV got us, we're hooked on that TV."

Mr Pete himself spends one afternoon a week working in the National Hansen's Disease Program museum as an ambassador, educating visitors about the disease and trying to dispel some of the stigma still associated with it.

He says there are still a few people who are scared when they hear the word leprosy.

"But they'll get into it," he says confidently.

He particularly enjoys talking to groups of children that visit the museum on school trips.

"They ask tough questions, they ask me about my hands, but I answer them," he says proudly. To him, knowledge about the disease will eventually beat the stigma. And the earlier you can educate people about it, the better.

"See, you know now, everything is good now. I'm doing good," he tells the children.

*Photographs by Phil Coomes*

## WORLD LEPROSY DAY

by Ymelda Beauchamp

January 31, 2010 marked the 57<sup>th</sup> annual celebration of World Leprosy Day. The celebration is observed mainly by the organizations involved in leprosy, and this is done to raise awareness and advocacy for the rights of people who have been and are affected by leprosy. The goals of these organizations also include restoring human dignity and pride, people's inherent human rights of justice, and all the possibilities that might exist to rid this misunderstood disease of the stigma that has always been attached to it.

The beautiful people of the International Association for Integration, Dignity and Economic Advancement (IDEA) extended the invitation, and through the generosity of American Leprosy Missions (ALM) I was able to attend and participate accompanied by my daughter Adrienne. On January 28, 2010 we were joined in Washington D.C. by pilgrims from NY, Connecticut and California. The mass was in recognition of the canonization of Fr. Damien in October held at St. Peter's Basilica in Rome, combined with the celebration of World Leprosy Day. Appropriately so, this event took place in the Basilica of the National Shrine of the Immaculate Conception, the largest Roman Catholic Church in the United States and North America and one of the ten largest churches in the world.

On Saturday under the cover of a snow storm we went to the Shrine to set up our information booth for American Leprosy Missions and IDEA. On Sunday morning, in spite of the snow, we had groups of people curious about leprosy visit the exhibitions, and visitors to the church and others who genuinely wanted to learn and help. We gave handouts; we answered questions and enlightened a good number of people. You would not believe the misconceptions people have about the disease.....

On Sunday, the high mass with the solemnity deserving of such an occasion, was celebrated by Monsignor Rossi and His Excellency Apostolic Nuncio Pietro Sambi, from the Vatican. The nights of Columbus and the Nights of Lazarus entered the Basilica followed by the entourage of priests, altar boys and His Excellency Pietro Sambi. Adrienne and I were lectors for the Readings of the Mass. The event was televised around the world including Canada and Mexico, it is said to have reached 30 million people.

At the end of the mass His Excellency spoke to the congregation about the present events which included a brief history of Fr. Damien's life. But a beautiful day turned ugly when His Excellency uttered the word "lepers" (Webster's definition...a pariah, unclean, outcast) time and time again. Monsignor Rossi followed, first by introducing Mother Theresa's successor present in mass, and then He continued with his blessings and praise to the different organizations around the world who are so dedicated to the work with leprosy. Again, out of the mouth of the high priest came the word "lepers" once, twice, numerous times. I lost count. For a fleeting moment my brain struggled to understand why priests would go through such a celebration and not comprehend the effect of the words they were using. So my pain turned to disgust as I realized that little did they know that "their" sensationalism of the word 'Lepers' served to cover up their ignorance.

While holding my daughter's hand who was very concerned about my feelings, I saw sitting among the parishioners people who give so much of their life and time to this cause, people who have touched not only my life indelibly but of so many around the world. I also saw the faces of those who have been affected by leprosy and who live very productive lives as responsible and law abiding citizens. Before me I saw years of struggle to rid leprosy of the word "lepers" vanished! Looking at the worshippers who were listening absorbedly to the words from their minister there was no doubt in my mind that a new wave of fear was unleashed among them.

After the ceremonies we were treated to refreshments and hors d'oeuvres at the Basilica joined by the congregation;



later in the evening we joined the participants and others who made the pilgrimage to DC for a Hawaiian luau at the hotel where the talk about the mass and unending questions about leprosy and the morning events continued late into the night.

On Monday morning still feeling somewhat disturbed by the language used by the priests we left Washington DC under a blanket of snow. As I looked out the window on the plane I thought of the battle ahead of us all to continue combating the stigma attached to leprosy, and the words of the great philosopher Marcus Aurelius came to mind: ***“This is a never-ending war; it is not a war we should not fight: It is just a war that never ends.” Stigma.***

I thank Fr. Pietre for suggesting the participation of people who have been affected by leprosy, IDEA, and ALM, for giving me the opportunity to be part of this beautiful event. I salute the wonderful people from Damien-Dutton and my Blessings to old acquaintances from so long ago who wish to remain unnamed. “Thank you for the dance.” Many thanks to Christina Miller from ALM whose positive and jovial persona was so welcomed...

### **Ymelda Beauchamp**

*\*The appeal made to the International Community and Authorities of every nation from the President of the Pontifical Council Archbishop Zygmunt Zמושy in his message for the 57<sup>th</sup> WLD did not include the elimination of the word “leper” from their doctrine, **it should have, but it did not.** It is my hope and prayers that one day soon the Catholic Church and other denominations around the world will work in solidarity for a change of language in the “creed.” It is after all, the church who gave birth and still contributes to the stigma attached to leprosy, thus perpetuating the marginalization of people affected by it.*

## **NHDP Outpatient Clinics - Snapshot**



The Chicago Hansen's Disease Clinic at Chicago was established in 1980. It serves patients in Illinois and the surrounding Midwest states. It provides diagnosis and treatment and focuses on prevention of deformity and disability. Our physician also serves as a consultant. Patients from out of state return to their referring physician with treatment recommendations.

Chicago Hansen's Disease Clinic is affiliated with the University of Illinois Hospitals and Medical Center Dermatology Department. Clinics are held at the outpatient care center. The staff is headed by Carlotta Hill MD. She has been working with Hansen's patients for more than 30 years. She

has extensive experience in her field and is well respected by all her patients. Fook Lee RN (Gladys) co-ordinates patient care, relates with physicians, other disciplines and patient families. The Hansen's Clinic is fortunate to have two specially assigned consultants, a Neurologist and an Ophthalmologist. The patients also have the benefit of an assigned physical therapist, occupational therapist and orthotics when deemed necessary.

## *Empowerment: Moving out of the Shadows*

By: José Ramirez, Jr., Managing Editor

For two days in June of 2010, sixty-five persons met for a historic summit in Manila, Philippines. This meeting has been in the planning phases for centuries. The first step taken to begin this journey to Manila began when some unnamed hero, a person affected with leprosy, complained, generations ago, about the cruel, unusual punishment and ostracism directed at persons suspected of having leprosy, now medically known as Hansen's disease. Those of us who attended this unique meeting will never be able to award him/her a prestigious, well-deserved medal. However, with the adoption of the later explained guidelines, which should have an impact on all unjustly, labeled individuals, we can all celebrate his/ her courage. The courage I reference, relates to actions that exhibit refusal--- refusal to be treated in an inhumane manner. This comprehensive concept of courage and refusal is what we now brilliantly refer to as empowerment.

In 2009, the World Health Organization (WHO) invited representatives from 150 different countries to review, discuss and approve guidelines related to reducing the worldwide disease burden due to leprosy. A very small portion of the guidelines addressed stigma, discrimination and empowerment. In light of this, the Sasakawa Memorial Health Foundation (SMHF) strongly advocated for the creation of a task force to plan for a meeting specific to empowerment. The task force comprised of WHO staff, one expert in research, representatives from SMHF, and two persons affected. This task force drafted the guidelines on empowerment to be critiqued, discussed, and simplified at the Manila meeting.

In Manila, persons from over forty-eight different countries, including persons affected, WHO managers and administrators, experts on stigma, partners who deal with other physical, mental and cognitive disabilities, independent observers, task force members, and a representative for the WHO Goodwill Ambassador for Leprosy joined forces to provide comments, criticisms and praise of the guidelines.

However, prior to the distribution of the guidelines and the arrangement of the meeting, the task force had to overcome five major hurdles. The first and most important hurdle was to determine the process of encouraging the participants in Manila to become co-owners of the document. The second hurdle was for the attendees to recognize the persons affected by leprosy present at the meeting as "experts" --- not as medical experts, but as experts in the world of leprosy. Third, was the challenge involving a guarantee from the attendees to accept and practice using person-first language. Additionally, the fourth hurdle was to ensure that the language is simplified and not riddled with medical terminology and jargon. The final challenge was to address the unique protocol practiced by WHO in recognizing leadership... all attendees are leaders in their respective communities.

The meeting was both frustrating and exhilarating. It was frustrating because many of the presentations made on the first day of the summit focused on personal stories and overcoming individual challenges. These stories, having been previously heard by many of the participants, created an initial belief that the meeting would not fully address the guidelines. The exhilaration came gradually as the participants realized that the meeting was intended to return the unique and beautiful distinctiveness to each person affected and liberate them from being simplified into one, solitary shadow. Additionally, the meeting created fuel for constructive discussions related to changes from persons being voiceless to being heard, from being given directions through policy to helping with the co-development and implementation of policy, and shifting from exclusionary to inclusionary practices.

The following guidelines, with accompanying strategies, were adopted by the participants and further refined by the task force members.

1. Stigma and Discrimination

Work with persons to evaluate whether words or images promote dignity or perpetuate stigma.

2. Equality, Social Justice, Human Rights

Work with people and their organizations to educate other people affected, program staff and community about human rights.

3. Information, Education, Communication (Raising Awareness)

1. Encourage people to serve as a role model for other affected people.

4. Advocacy

Work with people to promote equal access to services.

5. Counseling

Provide people with the opportunity to be trained as counselors.

6. Referral

Promote opportunities to work with health staff for effective referral services.

7. Resource Mobilization

Encourage the persons/groups to be involved in evaluating and advising resource mobilization/fundraising strategies to ensure they do not promote stigma.

8. Training and Capacity Building

Involve people to give training to program and project staff on how to involve persons affected in services.

9. Gender Issues

Work with people to advocate for equal rights and opportunities for men and women.

10. Planning and Management of Services

Promote the recognition that the people are experienced and knowledgeable on the disability and other related aspects, which are valuable to the program.

11. Prevention of Disabilities (POD)

Involve people to encourage others to go for examination at an early stage.

12. Rehabilitation

Work with people to promote the use of modern images and terminology, such as “physical empowerment” or “socioeconomic empowerment”

13. Monitoring Evaluation

Use experience of individuals who have a disability to help identify gaps in the public health system-- before, during and after treatment.

14. Research

Encourage people to work with researchers to ensure research methodology does not deprive people of their identity and that they are informed of their rights.

The three outcomes from the Manila meeting include:

1. Redistribution and review of the guidelines by the participants,
2. Publication and worldwide distribution of the guidelines by December 2010, and,
3. Preliminary evaluation of the implementation of the guidelines by December 2012.... Some countries have been implementing some or all of the guidelines for several years.

As a force member and the Chair of the summit in Manila, I will be providing additional updates in future issues of the STAR.



# Historical Report of the Leprosy Museum in Columbia

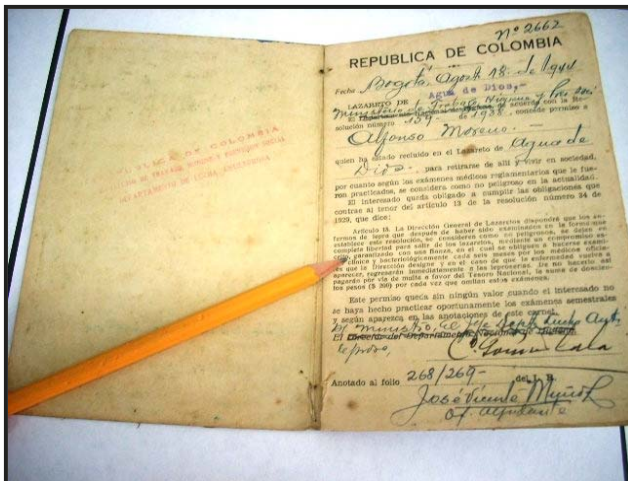
Dr. Hugo Sotomayor Tribin

**Agua de Dios** is a town in Cudinamarca, Colombia; it is 114 kilometers from Bogotá officially founded on August 19, 1870.

The founding of the town called Agua de Dios is largely due to a group of people affected by leprosy who were exiled by a community of inhabitants called To-caima, due to the fear of being infected with leprosy. The people affected by leprosy were forced to take over the land of a plantation by the named of “Agua de Dios.” to build their shelters. The first shelter was built by the Colombian State on the land of Agua de Dios bought by the government of Cudinamarca from the Republic’s ex President Dr. Manuel Murillo Toro to be



(Identification Card for children of Leprosy patients)



(Permit granted to live outside the Leprosarium)

selected as a Health Establishment previously designated with the names of Agua de Dios Leprosarium (Lazarus Home), Agua de Dios Home, and Agua de Dios Chapel. Presently it operates under two administrations; the first is the Municipality of Agua de Dios, and the second Agua de Dios Sanatorium States’ Social Firm. Its present population is approximately 13,000 people.

The creation of the Leprosy Museum in the Agua de Dios Sanatorium is the result of a favorable meeting of agreement and the interest of several people among which is pediatrician and medical historian, member of the National Academy of Medicine and who has acquired extensive experience as planner of expositions in the History of Medicine Museums, Hugo A. Sotomayor Tribin, of Juan José Muñoz Robayo hospitable Administrator and Manager of the Sanatorium, of Michel Faizal Geagea Medical Dermatologist and member of the Board of Directors of the Sanatorium; the efforts of the Honorable Senator of the Republic born in Agua de Dios ex-first mayor elect by popular vote of this city Nancy Patricia Gutierrez; Assessor to the senator Isabel Cristina Jimenez; and that of Ms. Patricia Devia Angarita also born in Agua de Dios and co-founder of the nongovernmental organization, Corsohansen.



(Permit given to an outsider to visit a patient)



(Autoclave-sterilizing equipment)

The achievement of the opening would not have been possible without the support of the whole community of Agua de Dios and the Sanatorium’s staff, above all of the Chief of Archives of the State’s Social Agency in Agua de Dios, Mrs. Teresa Rincón Sánchez.

The Leprosy Museum in the Agua de Dios Sanatorium opened its doors on August 21, 2009. Five months after decisions were made to establish it, and three months after initiating the process of so-



(Interior of the first site of the Museum in Medical House)



(Exterior of the first site of the museum)

cialization in the community of Agua de Dios. The first site was the conference building in the recreation quarters of the Medical Home. Here it remained until January 31, 2010, when the welcoming by the community shaped the state of affairs for which the agency of the Sanatorium decided to rehabilitate the old but beautiful Carrasquilla Building where the Museum was moved to on the same date, to correspond with the last Sunday of the month in January when World Leprosy Day is celebrated.

The Medical History Museum of Leprosy is still in quest of financial support in order to equip the sector with adequate furnishing, keeping in mind that the exhibition of objects has contributed much to the visitors understanding of the museum and the history of leprosy in Columbia.



(This is the building that now houses the Leprosy Museum)

translation by  
Ymelda Beauchamp

## Morris – A Poem

by Eve Rifkah \*

February 23, 1908

My Dearest Esther,

Why is it you don't write? This disease not curse enough, you curse me with silence? Not enough I live without your dear face? And our children, good-natured Rachel, she must be great help to you and Clara, her hair still red of spun gold? Must be young men calling? Why don't you tell me? You are getting by? Hymie is helping? Such a brother, he should put a foot in front of the other and get someplace.

Esther, I can't bear this. Every day the mail boat comes from New Bedford. Mrs. Parker hands out the letters, none for me. I can't help the tears. This illness not my doing. In sickness and health we married? Only a letter, all I ask, to see in words what I cannot imagine. My boys, what have become of my boys? Mendel in school? Harry a job with the printing press? And Nathan, the quiet one still buried in books? He studies hard for his Bar Mitzvah?

Over and over I shut my eyes, see you and the girls screaming. Clara hiding her face in her scarf, teeth chattering, cold in July. Already you killed me? You say Kaddish? Light candles? Oh Esther, I am still here breathing dreaming your dark eyes. Please, I beg you take pen to paper send me your blessings so I may caress your words, smell the ink, touch the flap where your tongue licked the seal. This too much to ask?

Your still loving husband.

Morris

- Ms. Rifkah wrote a book of poetry paying tribute to the persons buried at the now closed Penikese Island Leper Colony. The location of a "leper colony" was originally considered at the Tewksbury Insane Asylum. This idea created a greater level of revolt in Massachusetts than the Boston Tea Party. The "colony" was operated by the State of Massachusetts from 1905 – 1921. In 1921, 13 of the remaining patients were relocated to the national leprosarium at Carville.

Eve Rifkah, Outcasts - the Penikese Island Leper Hospital 1905-1921, Little Pear Press, Seekonk, MA, 2010, p39.



## FACTS ABOUT HANSEN'S DISEASE

National Hansen's Disease Programs, Baton Rouge, Louisiana

### 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 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 dapsone, rifampin, and clofazimine, is the recommended treatment for HD in the U.S. The rising incidence of sulfone resistant disease necessitates

treating all patients with more than one drug. Treatment rapidly renders the disease 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](http://www.hrsa.gov/hansens)

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

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## The International Gandhi Award- 2009

By: Sara Millimet, Rice University

*As a student at Rice University in Houston, TX, I am part of a new program called the Poverty, Justice and Human Capabilities program. It is a program centered around Amartya Sen and Martha Nussbaum's development of the capabilities theory. As part of the program, the program manager developed an internship with the Mental Health and Mental Retardation Authority of Harris County. Here, I have been fortunate enough to work with José Ramirez, Jr. The position has proven advantageous in that I have not only gained an understanding of mental health and mental retardation (intellectual and development disabilities), but have learned about Hansen's disease and the global population that it has affected. Prior to working with Mr. Ramirez, I had little knowledge or experience with the disease. I did not know anyone affected or how common it was, but I also had not been exposed to the fierce stigma of the disease. Therefore, Mr. Ramirez has taken the time to educate me on the scientific and the social dimensions of the disease mean while sharing his deep desire to reduce stigma of leprosy and other afflictions. Thus, it is with great appreciation and admiration that I write about the recipients' of this year's International Gandhi Awards.*

The Nobel Peace Prize, awarded by the Norwegian Nobel Committee, is often thought to be the most publicized and renowned award honoring those who have devoted a substantial amount of time and energy towards promoting peace between nations. Less promulgated, aside from in the world of leprosy, is the International Gandhi Award. Nonetheless, the recipients of this award, awarded by the President or Vice President of India each year, are no less deserving of formal encomium and global acclamation.

The International Gandhi Award is bestowed upon persons or organizations that have made exceptional contributions to leprosy work and improving the lives of persons affected by leprosy. Mahatma Gandhi dedicated both his time and effort to serving members of the leprosy community, at a time when little was known about the disease. Gandhi selflessly provided care to Parachure Shastri, a distinguished scholar of India, who was unjustly ostracized when he contracted leprosy. Thus, he created special communities for people affected by leprosy, where they could live without facing the inhuman cruelties of the outside world. The Vice President of India, Shri M. Hamid Ansari, explained Gandhi understood both the medical and the social dimensions of the disease, as he worked to reduce the stigma associated with disease and sought to reintegrate persons affected with leprosy into the general community (Press Information Bureau, Government of India, 2010). Gandhi notably recognized the human rights violations common in the lives of persons affected with leprosy. The award was established on 1986 in honor and memory of Gandhi.

This year's awards were graciously given to Dr. Vijay Kumar Pannikar, the former Team Leader of the Global Leprosy Programme and the nongovernmental organization (NGO) Vidarbha Maharogi Sewa Mandal. The recipients were selected on April 20, 2010 and the presentation of awards occurred in Wardha on July 1, 2010.

Dr. Pannikar has showed admirable devotion to the community affected by leprosy in his 34 years of service. He began his career as a Medical Officer at Dr. Bandorawalla Leprosy Hospital providing in-patient care to persons affected by leprosy at a time when most physicians were disinclined if not opposed to doing so. He continued his venerable efforts at Scheiffen Leprosy Research and Training Center where he provided community based services and trained additional personnel who will eventually aid in leprosy elimination program. He initiated his work with the World Health Organization in 1990, as a Consultant for the WHO leprosy Unit, and continued meritorious work with the global organization for the next twenty years.

More recently, Dr. Pannikar, coordinated leprosy related meetings for the World Health Organization and the Technical Advisory Group (TAG) meetings of leprosy experts from all over the world. According to José Ramirez, Jr., Dr. Pannikar was the first World Health Organization (WHO) team leader to extend an invitation to someone affected by leprosy address the TAG. Consequently, he opened up the opportunity to persons affected by leprosy to be part of the effort to reduce stigma and regain human rights. José Ramirez, Jr. speaks admirably of Dr. Pannikar's passion and determination to correct the stigma of leprosy that has been bred over the centuries.

In April 2009, Dr. Pannikar coordinated the WHO Global Strategy for Reducing the Disease Burden Due to Leprosy held in New Delhi, India. 150 representatives from around the world in addition to other experts met to discuss and present ideas on stigma and discrimination. Prior to his retirement, Dr. Pannikar recommended that another meeting specific to empowerment be held. In June 2010, persons affected by leprosy from fifteen different countries, experts on stigma from six countries, and various other participants from the WHO met in Manila, Philippines for the WHO Guidelines for Participation of Persons Affected by Leprosy. The participants brilliantly developed guidelines and strategies for empowerment of persons affected by leprosy, according to Dr. Pannikar's counsel. These strategies and guidelines can beneficially be extrapolated to empowering people with any disability. Dr. Pannikar was an esteemed guest at this secondary international meeting.

The editorial board of *The Star* extends our sincere congratulations to Dr. Pannikar on this marvelous and well-deserved accomplishment.

Press Information Bureau, Government of India. (2010). "Vice President Presents International Gandhi awards-2009 at Wardha." Retrieved on July 6, 2010 from <http://www.pib.nic.in/release/release.asp?relid=62953>

## EVERSLEY CHILDS SANATORIUM, CEBU

By: Ymelda Beauchamp

My visit to Manila came following an invitation from the World Health Organization Global Leprosy Programme. The invitation was extended to people affected by leprosy to participate in a Summit Meeting to review and approve guidelines to strengthen the participation of persons affected by leprosy in leprosy services. The meeting took place on June 9 and 10.

On June 11 Dr. Ma.Gemma C. Cabanos, Executive Director at the Philippines Leprosy Missions, Mary Nevis of TLM and yours truly took a flight to Cebu Island for a visit to Eversley Child Sanatorium and the Leonard Wood Research Laboratory. This invitation to visit Cebu was facilitated by Mr. Jim Oehrig, Chief Programme Officer and Acting CEO of American Leprosy Missions.

Eversley Childs Sanitarium in Cebu Island was the second largest hospital and community for people affected by leprosy in the Philippines. The sanitarium was once residence to people who were exiled from their homes and communities because of their disease. It is now home to 150 residents who have been cured of leprosy for many years but have chosen to remain in Eversley. For many Eversley is their permanent home, for others a place of rest and for many others a place to just....be....This is where the cure for leprosy Multiple Drug Treatment (MDT) was developed between 1981 and 1986. The Leonard Wood Memorial, on the same grounds has operated a research laboratory on the island of Cebu since 1928. There is Training and Treatment at the Cebu Skin Clinic, which diagnoses new cases of leprosy and whose patient care is financed by American Leprosy Missions donors. The LWM has coordinated research and training on a worldwide basis, supported activities in epidemiology, chemotherapy, diagnosis, microbiology, and immunology and of course the study of a vaccine for the prevention of leprosy.

My two companions and I arrived in Cebu at 7:00 am on Friday 11, waiting for us was a driver from the clinic, and after greetings were exchanged we began the drive through a colorful and busy city. On the road we passed several signs with the word "Mabuhay" which means "hello" and "welcome;" we also saw produce stands on the roadside selling vegetables, fruit and cages for roosters. As we drove my anxiety to see the hospital increased, and I wondered why most leprosy hospitals are in such remote locations; these locations seem to have been chosen according to a global plan to ensure quarantine, and an indefinite separation from society. Eversley Childs Sanitarium is no exception; it is located along a monastic line from the city.....

A gravel road and a guarded entrance told me that we had entered the grounds. Upon entering the gates I was reminded of a similar place far from Cebu. After the gate it was the crushing noise of the car going over the gravel road; combined with the rushing of humid heat and an unforgettable mildew smell....low, deep and familiar, the white buildings spread out as well as green foliage appeared behind the houses ....My vision blurred with tears as unbidden memories of Carville came to mind, like a ghost long submerged. Sometimes I am wistful for the times at Carville, but I guess everyone misses their youth.....

At the Eversley clinic we were greeted by the staff and residents with arms open wide and beautiful warm smiles. In time for clinic we were invited to sit in as children were examined. It is apparent that the staff is competent, knowledgeable, reassuring and seems highly experienced at what they do. We were told about the follow up such as home visits when people fail to keep appointments and the involvement of all staff member (including drivers) in the early detection of leprosy. The staff conducts health education for the person affected by leprosy and family members. After clinic the ladies and I were treated to a very delightful lunch of sea food and fruit prepared by local vendors, and then we went for a visit to the Leonard Wood Memorial Laboratory.

Unfortunately for us it was quite late in the day when we were finally able to meet with the IDEA group, residents, children and young adults. Children and adults seemed eager to see us; we asked about their life in Eversley, it seems that everyone present expressed a personal acquaintance with the secrets of survival on the outside world while living in leprosaria. Though quite sadly, their concerns and needs were not voiced due to time constraints, however, one could feel the vulnerability in their voice when describing "a life with struggles."

We had hoped to see the infirmary, the housing area, and the grounds in general but the day seemed to disappear all too quickly. It is easy to understand that for such a visit one needs more than just one day; so much to do, so many questions unanswered, so many people to meet, so many stories waiting to be told, time flew as it often does, so after our meeting we said our good byes, we exchanged emails promising to keep in touch and of course on my part, a promise to return.

As we drove out of the gate it became clear to me that the children and young adults of Eversley Childs Sanitarium are now the keepers of their heritage, stories of their ghostly natives before them, their national history and the absent past which must be told and preserved for future generations and the world to know.

Thank you ALM for this opportunity!

## THE STAR PUBLICATION AND ITS ASSOCIATION WITH THE FORTY & EIGHT by George “Doc” Willis

The STAR magazine was created by Carville resident Stanley Stein after his arrival at the antebellum plantation in Carville, Louisiana as a way to reach beyond the fence to the larger world. Resident Johnny Harmon ran a photo business and was a photographer for the STAR, which had a circulation of 10,000 when Mr. Stein died in 1968, and later had as many as 160,000 subscribers. The STAR has provided a window into hospital life at Carville and to leprosy-related care throughout the world. The STAR has been widely read by leprologists, researchers, writers, missionaries and persons affected by leprosy.

The Forty & Eight and the American Legion purchased a printing press and other equipment in 1943 to help the patients carry on “their fight against the ignorance which surrounds this disease. In 1947, the Forty & Eight decided to accept sole responsibility for the funding of all publication costs for the hospital’s patient-published magazine. The year of 1994, marked the 100<sup>th</sup> year founding of the Gillis W. Long Hansen’s Disease Center in Carville, Louisiana, and the 50<sup>th</sup> anniversary of the Forty & Eight’s continued sponsorship of the STAR.

In 2010, sixty-six years after establishing support for the Carville STAR Program, the magazine is stronger and more involved in erasing the *stigma* of Hansen’s disease throughout the world. In support of the STAR publication and the Carville STAR Program, several fundraising efforts have been initiated. They include the following:

- **BUY A COUNTRY** – a donor subscription plan that allows a Voiture or Cabane (or individual Voyageur or Dame) to donate \$50.00 and send 12 one-year subscriptions to a specific country of the donor’s choice. This donor receives an attractive *BUY A COUNTRY* certificate suitable for framing from the National Directeur.
- **THE STAR MAINTENANCE FUND** – this fund is maintained by Voiture Nationale, with the Correspondent Nationale charged with the responsibility of administering the fund. It is supported by sales of Carville, STAR Pins. The pins are available through the Grand Carville STAR Directeur. As your Voiture Locale Directeur to order some today.
- **MUSEUM FUND** – this is the newest project. It maintains the Carville STAR Museum and special projects at Carville, Louisiana. This is a living history of THE STAR and the history of Hansen’s disease. Donated funds helped to completely refurbish the museum, provide attractive signs and banners, souvenir pins for visitors, and the current design of a flag for the museum, with the 40 & 8 emblem.

**CARVILLE STAR SUBSCRIPTIONS** – The STAR publication is printed twice a year and the \$2.00 subscription is good for one year (summer and winter issues). Copies of past issues only can be accessed online at [www.fortyandeight.com](http://www.fortyandeight.com) Additional information concerning the Carville STAR Program can be found on the Nationale website at [www.fortyandeight.org](http://www.fortyandeight.org) main page, scroll down to *Programs*.

- **IN HONOR OF, MEMORY OF** – readers may made a general donation to the Carville STAR Program and receive an attractive citation *In Honor Of* a worthy Voyageur or Dame, or *In Memory Of* a Voyageur or Dame that has transferred to Voiture or Cabane Everlasting.

**FUND RAISING IDEAS** – these vary from pin sales, to raffles, 50/50 drawings, bingo, dinners, dances, golf or fishing tournaments, bake sales, and casino nights. Many Voitures and Cabanes include a \$2.00 STAR subscription in their yearly membership dues.

Recently the Nationale Directeur of the Carville STAR Program discovered Hansen’s Disease Clinics in the United States have not received subscriptions of the STAR, nor have the health officials of our fifty states. Therefore, the 40 & 8 has initiated an effort to provide copies to these locations. *BUY A STATE* or *BUY A CLINIC*, for \$50.00 will result in subscriptions of the STAR to the Surgeon General of the state or clinic designated. The thirteen (13) clinics are located in the following cities and states: Burlington, MA; Los Angeles, CA; Martinez CA; Seattle, WA; Dallas, TX; Houston, TX; San Antonio, TX; Harlingen, TX. There is also one located in San Juan, Puerto Rico.

*(Some of this article is a reprint from the Baton Rouge Advocate, January 20, 2008)*



## **HANSEN'S DISEASE CLINICS**

### **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  
Public Health Nurse - Ms. Stephanie Burns, RN,  
D.N.C.

### **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  
Public Health Nurse – Gladys Lee, RN

### **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. Thomas Rea  
Public Health Nurse - Ms. Helen Mora, RN  
Occupational Therapist - Rob Jerskey

### **MARTINEZ HD CLINIC**

Contra Costa Regional Medical Center  
Outpatient Specialty Clinic  
2500 Alhambra Avenue  
Martinez, CA 94553  
PH: (925) 313-6726  
Fax: (925) 313-6465  
Primary Physician - Drs. Sutherland/Saffier  
Public Health Nurse - Ms. Elise Judy, RN  
PH: (925) 370-5868  
Fax: (925) 370-5529

### **MIAMI HD CLINIC**

Jackson Memorial Hospital  
1611 N.W. 12<sup>th</sup> Avenue  
ACC East – 2<sup>nd</sup> Floor  
Department of Dermatology  
Miami, FL 33136-1096  
PH: (305) 585-7348  
Fax: (305) 585-6397  
Primary Physician - Dr. Anne Burdick  
Public Health Nurse - Ms. Gail Chepenik, RN

### **NEW YORK HD CLINIC**

Bellevue Hospital Center  
Department of Dermatology  
Room 17-N-7  
462 First Avenue  
New York, NY 10016  
PH: (212) 562-5670  
Fax: (212) 263-6423  
Primary Physician - Dr. William Levis  
Public Health Nurse - Ms. Trudy Spencer, RN  
PH: (212) 562-6096  
Physical Therapist - Mr. Louis Iannuzzi, P.T.,  
C.Ped.

### **PHOENIX HD CLINIC**

Maricopa County Health Department  
1645 East Roosevelt Street  
Phoenix, Arizona 85006  
PH: (602) 506-6650  
Fax: (602) 372-3862  
Primary Physician - Dr. Ronald Pust  
Public Health Nurse - Eileen Smith, RN  
PH: (602) 506-5070  
Physical Therapist - Tracy Carroll, MPH

### **SAN DIEGO HD CLINIC**

HHSa, North Central Regional Center  
5055 Ruffin Road  
San Diego, CA 92123  
Mail Stop: N-513  
PH: (858) 573-7338  
Fax: (858) 573-7325  
Primary Physician - Dr. Erik O. Gilbertson  
Public Health Nurse – Ms Gina Sandoval, RN,  
PHN

### **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  
Public Health Nurse - Ms. Sonia Santos-Exposito,  
RN  
Ph: (787) 758-2525, ext. 5503

### **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  
Public Health Nurse – Marlene Skinnell, RN  
Physical Therapist - Tom McClure, PT, CHT

### **TEXAS HD CLINICS**

Department of State Health Services  
Hansen's Disease Program  
P. O. Box 149347  
Austin, TX 78714-9347  
PH: (800) 252-8239  
Fax: (512) 458-7787  
Nurse Consultant: Ms. Linda Brown MS, RN  
PH: (888) 963-7111 Ext.: 6331  
Officer Administrator: Kirbi Woods  
PH: (888) 963-7111 Ext.: 6608

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  
Public Health Nurse - Ms. Nancy Bernstein, RN,  
BSN,

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  
Public Health Nurse – Marion Matsu, RN, CCM  
Main: (832) 393-5173

Texas Center for Infectious Disease  
2303 S. E. Military Drive  
San Antonio, TX 78223  
PH: (210) 531-4576  
PH: (210) 531-4295  
Fax: (210) 531-4508  
Appointment Secretary (210) 531-4526  
Physician - Dr. Robert N. Longfield  
Physician - Dr. Adriana Vasquez  
Physician - Dr. Lynn Horvath  
Public Health Nurse - Ms. Debbie Mata, RN  
Ph: (210) 531-4295

Department of State Health Services Region  
(HSR) 11  
601 W. Sesame Drive  
Harlingen, TX 78550  
PH: (956) 423-0130  
Fax: (956) 444-3295  
Physician - Dr. Richard Wing  
Public Health Nurse – Grace Flores, RN

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

HD is essentially a disease of the peripheral nerves, but it also affects the skin and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, muscles, bones and testes.

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

### Where is HD Found?

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

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

(See listing of clinics.)

### How Does HD Spread?

While this aspect of the disease remains a medical mystery, the most commonly accepted theory is that it is transmitted by way of the respiratory tract, and abraded skin. The degree of susceptibility of the person, the extent of exposure, and environmental conditions are among factors probably of great importance in transmission. Most specialists agree that 90% or more of the world's population have a natural immunity to the disease. Persons working with HD contract the disease only rarely. Cases of HD which respond satisfactorily to treatment become noninfectious within a short time.

### How is HD Treated?

Although the sulfone drugs, introduced at Carville in 1941, continue to be an important weapon against the Hansen bacillus the rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Usually rifampin and sometimes clofazimine or ethionamide are given in addition to dapsone. Treatment rapidly renders the disease noncommunicable by killing nearly all the bacilli and these dead bacilli are then cleared from the body within a variable number of years.

"An updated version is printed on page 11"