

The Star

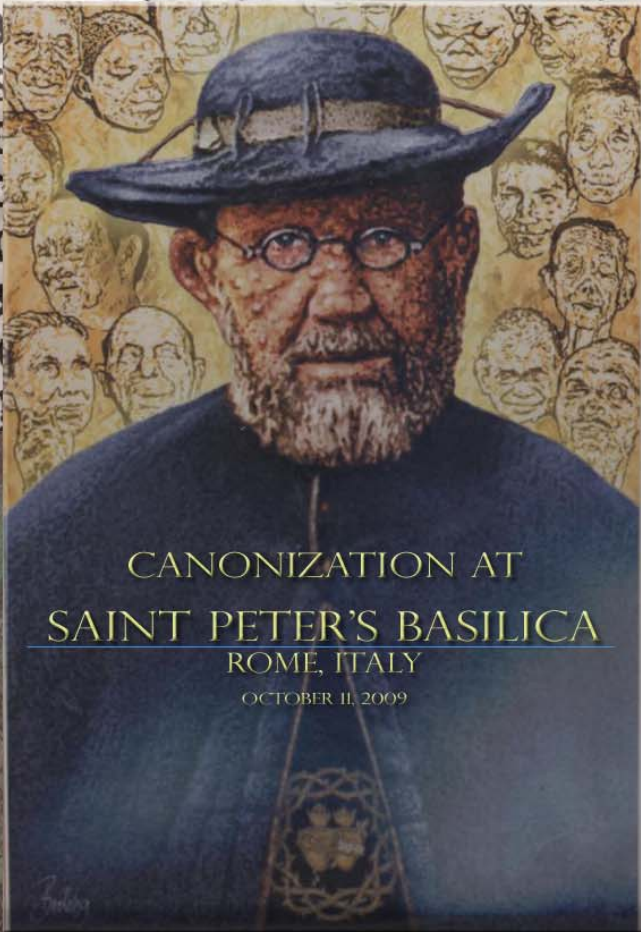
RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

JULY - DECEMBER
2009
VOLUME 64 - 8

and we went swinging across the waves, and finally chose a fit moment for leaping. Father Damion helped me up the hearty welcome shone from his kind

“ He is now forty-nine years old, a strongly-built man, with black curly hair and a short beard, turning gray. His face has been rather handsome, with a full, smiling mouth and a short, straight nose; but he is a good deal disfigured by leprosy, to the extent badly as to make it anything but a

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CANONIZATION AT
SAINT PETER'S BASILICA
ROME, ITALY
OCTOBER 11, 2009



CANONIZZAZIONE
PIAZZA SAN PIETRO, 11 OTTOBRE 2009

face, and his eyebrows had sunk, and his hands and feet were swollen with disease, but he assured very bad, little or no pain since they he told them to sing to sing for some time for months. One is relieved, even if it should be but it is impossible not to fear that the disease will progress the disease attacked the lungs or some other part of the body that the remedy comes too late. I am assured here that gurgun oil is the best remedy which grows plentifully in the islands. Its efficacy was first proved by Sir Donald Stewart, and I am assured by Sir Donald Stewart, who was then Governor of the islands, and who has

designed by Anthony Mercurio Scarlattella

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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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Cover Design: Anthony Scarlatella from Houston, Texas designed the cover, which includes background print from a 1889 article published in the New York Times on Father Damien, the photo of Father Damien used by the Vatican to create a giant tapestry for the canonization, and the cover of the “Saint Book” distributed by the Vatican to all who witnessed the canonization inside St. Peter’s Basilica.

Saint Damien Resolution

by José Ramirez, Jr.

October 11, 2009 was a day of jubilation at Vatican City with the canonization of one of our brothers affected by leprosy. However, for members of IDEA, it was not a day to relax. With the continued existence of stigma, IDEA members from Brazil, England, Ghana, India, Italy, South Korea, the United States, and ILEP representatives from Britain and Italy who attended the ceremonies, read the “Quest for Justice Resolution” in St. Peter’s Square. The resolution below was written, was an effort to counter all of the myths about leprosy and the use of the “I” word following the canonization ceremonies. This reading was described in stories published by the New York Times, International Herald Tribune, and London Times. All across the world, the works of persons affected by leprosy were recognized. However, the words from three widely respected newspapers do not reach all continents.

So with this in mind, the board members of IDEA sat under the gigantic columns embracing St. Peter’s Square. The columns, covered with gleaming white travertine marble recycled from the huge Gladiator Coliseum, supported our tired backs to discuss ideas for 2010 and beyond.

The energy from the spiritually uplifting event could not mask the dilemma confronting the future of IDEA, as well as other non-profit organizations, particularly those dealing with grassroots, advocacy issues. With the current global economic situation, the board discussed strategies for providing support to IDEA’s branches in 23 different countries, the continued support of programs, and the display of the exhibit “Quest for Dignity.”. Bernard Punikai’a, one of the founders of IDEA once described the value of the exhibits in the following manner: “When you look at a photograph, you see how a person looks. When you read their quotations, you see the heart of a person, and then it becomes complete.”

With renewed vigor and the spiritual presence of Saint Damien, the meeting adjourned. In unison, the group agreed that “adjournment” meant that there always be other events, other ideas, and many more days and years of concerted efforts to continue the battle against stigma and social injustice.

A Quest for Justice

A Resolution on the Occasion of the Canonization of Father Damien

The canonization of Father Damien De Veuster provides an unprecedented opportunity to focus on the world’s attention on the modern day realities of leprosy. At the same time, discussing his work with the people of Kalau-papa enables us to promote issues related to justice and human rights that were the cornerstone of his work. As we honor his memory, it is equally important that we honor his commitment to promoting the equal and inalien-

able rights of every human being.

Today, 120 years after the death of Father Damien, people around the world affected by leprosy continue to be denied the basic rights outlined in the Universal Declaration of Human Rights, including: The right to home, the right to family, the right to work, the right to education, the right to nationality, the right to a standard of living adequate for health and well-being, and the right to be free from degrading treatment.

Father Damien insisted on justice. He insisted that people should not be deprived of their rights or value as human beings because they had a disease. He saw the value, dignity, and inspiration in each person.

Discussing Father Damien's life and work in the context of the human rights issues facing people affected by leprosy today provides an important bridge between the past and present. The Church has always played an important role in supporting people who have had leprosy. The canonization of Father Damien provides the Church with the opportunity to circulate a timely message throughout the world about the basic human rights of individuals affected by this disease.

As we honor the work that Father Damien did more than a century ago, it is essential to make it clear that today:

- 1) Leprosy is curable. The biggest problems facing people affected by leprosy are related to outdated images and prejudice and discrimination that result in widespread human rights violations.*
- 2) The term "leper" is not appropriate in modern times. We must ensure that in talking about Father Damien we use the language of today, not of 100 years ago. We must urge the public to recognize that although the word "leper" was a historical term widely used in Father Damien's day, it has taken on increasingly negative connotations in the last century. We must agree that no one should be referred to by this term today as it violates their right to be free from degrading treatment.*
- 3) People who have experienced leprosy are equal partners. Father Damien worked with the people of Kalaupapa as equal partners. They built houses together, formed funeral associations together, and planned religious celebrations together. Working side by side, they welcomed new arrivals to Kalaupapa with hot steaming coffee. Father Damien's legacy encourages us to continue to promote partnership as an important means of ensuring the full and equal participation of individuals whose lives have been challenged by leprosy.*

As we approach the canonization of Father Damien and proceed into the future, we resolve to utilize his legacy fully to promote the basic rights of all individuals, particularly those who have had leprosy.

Resolution adopted in Rome, 11 October 2009 and signed by representatives of IDEA, ILEP, AIFO, and 40 & 8.

Range of Light Toward Sainthood

by José Ramirez, Jr.

On May 31, 2000, I threw a lira coin over my left shoulder into the Trevi Fountain and wished for a return to Rome. Earlier in the day I had attended services at St. Peter's Square and was scheduled to have a "special audience" with Pope John Paul II. Regrettably, this meeting was nixed by unforeseen protocol. I still managed to receive the Pope's blessing as we made eye contact and he made the sign of the cross when he was escorted by security personnel to within 10 feet from my seat.

The trip to Rome in 2000 was done as USA Coordinator for IDEA (International Organization for Integration, Dignity, and Economic Advancement). IDEA is an organization of persons affected by leprosy with branches in 23 countries.

AIFO, an anti-leprosy organization based in Italy, had informed IDEA that the organization was being recognized for "courageous work in impacting change in the field of leprosy." Dr. Gopal from India and I were invited to receive the award on behalf of IDEA.

My wish to return to the lovely city of Rome did not materialize until 9 years later. The return trip was made as Managing Editor of The Star and on courtesy of the 40 & 8. The trip was for the purpose of witnessing the canonization of Father Damien de Veuster at St. Peter's Basilica.

Father Damien had a much longer wait in making his first trip to Rome. He arrived 120 years after his death at Kalaupapa Settlement on Molokai Island, Hawaii to be united with four others also awaiting canonization.

Father Damien was featured on a huge tapestry in front of the basilica facing St. Peter's Square, along with the four others similarly canonized. Thirteen years of his life were dedicated to working with thousands of persons affected by leprosy. Many with leprosy experienced a sad and oftentimes brutal death. They were isolated on a peninsula surrounded by high cliffs and a rough ocean. They lost families and their identities. Father Damien offered physical and spiritual care. He used his carpentry skills to build homes and a church which still stands. He used his compassion and understanding of both physical and emotional pain to soothe the souls of so many who died. Father Damien died from complications of leprosy in 1889.

The canonization came after 4,000 years of seeking acceptance among the living. Persons with advanced stages of leprosy appear to have been on Michaelangelo's mind as he painted the "Resurrection of the Dead" on the lower left hand side of Last Judgement at the Sistine Chapel. Saint Damien has made it possible for those of us affected by leprosy to resurrect our identity as human beings.

The city was dressed in gala, there were religious festivities everywhere. Two nights before the big event, there was a piano/violin concerto of classical music in memory of Father Damien, hosted by the Rome chapter of AIFO. The concert was held in "old Rome" in a church built in the early 1300's. The acoustics here are of such high quality that the church was transformed to a concert hall, which brought to mind the changes that Father Damien made in his own life. He learned the language of the people of Kalaupapa and became one of them. He worked alongside the residents, building homes, counseling them, and treated their disease with the compassion of a gentle nurse. Later on, their disease became his own disease as well.

The night before the canonization, my wife, son, niece (Magdalena, J.R., and Cindy Cuellar), and I attended a special mass. The service was at the Santa Maria Minerva Basilica built in the 1400's. The church was filled with people representing many ethnic groups, all wearing their country's traditional garb. During the service there were many moments of sadness as a choir from Hawaii sang in their native tongue; we could visualize Bernard Punikai'a, (our dear friend and strong advocate from Kalaupapa Settlement) raising his beautiful voice with the choir. After the mass, members of many organizations from five different continents gathered outside the basilica and released hundreds of colorful balloons as we shouted in unison, "Aloha."

As many of the readers of The Star may know, a visit to St. Peter's Basilica can leave one breathless. The prominent arches, the angles, painted on marble interconnecting with the ominous sculptures of Mary sadly holding the lifeless body of her son; the vivid colors of the frescos by master artists and the huge spiral columns at each corner of the main altar, all this can make one feel very small indeed.

However, the witnessing of the canonization itself, the pomp, the glory, the colorful vestiges and the omnipresence of the Pope reading the liturgy, the solemnity of it all, made me feel as if I had been transported to Heaven - for a brief reunion with my deceased parents. I closed my eyes and finally after so many years I let peace ebb into my body.

Someone said to me, "This is a once in a lifetime experience that is surpassed only by the ritual of crowning a new Pope."

I sat 10 rows from the altar, 10 rows from Pope Benedict XVI recognizing Father Damien as a saint. The many faces around me appeared to be serene, listening as Father Damien was acknowledged for his commitment to human rights and deep devotion to persons affected by leprosy while maintaining his loyalty to his ministry. I sat 10 rows where I could hear His Excellency whose voice seemed to gain strength and clarity as he pronounced the word "leper" seven times during the Holy Mass. Seven times he uttered it, seven times I cringed. Seven times I prayed for change in the dogma and ecclesiastical world.

In the rows in front of me were the King and Queen of Belgium (Damien was born in Tremolo), the President of Poland (Father Felinski was also canonized as the Saint of orphans and the destitute), the Prime Minister from Spain (Father Francisco – Saint of Missionaries and Father Rafael – Saint of Youth), Prime Minister from France (Saint Jugan – Saint of the poor), and Miguel Diaz, America's first Hispanic Ambassador to the Vatican.

The canonization of Saint Damien will hopefully bring renewed justice to the millions who continue to face discrimination. It will definitely bring a sense of peace to those who have died, such as my mother who was dramatically impacted by my diagnosis of Hansen's disease. For decades, she believed God was punishing her through me for some unknown sins. The "Leper" Ten Commandments "created by the church to isolate persons with leprosy (#1...forbidden to enter churches...)" and Leviticus' 13:1-2, "...the man who bears the sore of leprosy...shall cry out 'Unclean, unclean'..." shall hurt her no more.

October 11, 2009 woke us up with heavy rain and our arrival at St. Peter's Square was met with gray skies. By the end of the canonization mass, the sky was clear and the sun bright. As thousands exited St. Peter's Basilica and the Square, I sensed that Saint Damien walked alongside the crowd. He was yelling – Stop the injustices and discrimination. Heal the pain of stigma. Correct the cruel myths about persons affected by leprosy. Unite in restoring dignity and respect.

Saint Damien has made winners of all of us affected by leprosy. The members of the 40 & 8 made it possible for me to take this beautiful trip towards healing and report on this day of acceptance. Similar to Stanley Stein's creative motto for The Star, "Radiating the light of truth about Hansen's disease," Saint Damien now shines brightly with a huge range of light in the world of leprosy.

The only drawback to the canonization was that the Story of Saint Damien metastasized to mainstream media, resurrecting labels that come with the "l" word. So, the battle against the web of guilt (sin) by association (leprosy) continues.

The morning after the canonization, three AIFO representatives and two colleagues with leprosy (Zilda Borges from Brazil and Kofi Nyarko from Ghana) met with Dr. Donato Marra at Quirinal Palace, Italy's equivalent to the White House. Dr. Marra is Secretary General, or Chief of Staff for Italy's President Giorgio Napolitano. Dr. Marra met with us for 25 minutes and expressed a genuine compassion for persons affected by leprosy. He agreed to work against all forms of discrimination. We departed the meeting with a strong embrace of friendship and a presentation of three gifts: a wooden sculpture from Ghana representing family and unity, a copy of the book Father Damien... written by Anwei and Henry Law and translated to Italian, and a copy of my book, Squint: My Journey with Leprosy.

Upon our return from Rome, we drove immediately to Baton Rouge for the (37) Louisiana Book Festival. We attended an author's reception and shared book titles. Comments immediately led to "You don't look like a 'leper'." With patience, we would explain that the "look" they referenced was a stereotype and that the "l" word was offensive. In spite of their skill with words, they continued to refer to me by the "l" word.

The next day we shared our experiences with 75 attendees at our book signing session. In reference to one of my comments about the continuous use of the "l" word the previous night, one of the authors in attendance challenged me. She stated that I was wrong in attempting to stop the use of the word "leper." With Father Damien's canonization, I should wear the word like a "badge of honor," she said.

My response was threefold ¹the origins of stigma are based on language and appearance and how leprosy appeared hundreds of years ago and this view has no place in contemporary times; ²none of the dictionaries of the world define "leper" in positive terms and thus I did not wish to be known as a "pariah," "untouchable," "menace to society," or "outcast;" ³and persons with HIV/AIDS, H1N1 and those caught violating the rules of steroid use have been describing their experiences with family, friends, and media as being "treated like a leper." When spelled in reverse it spells "repel." There is no beauty to this word. So, a "badge of honor" – absolutely not.

There are no pretty colors to paint ugly, and stigma is ugly. Collectively, we must work to overcome the shame of stigma. The Star and the 40 & 8 still have much work to do in the area of stigma.

Book Reviews

Father Damien... "A bit of taro, a piece of fish, and a glass of water,"

Many books and articles have been written about Father Damien Da Veuster, who has oftentimes been portrayed with just reason, a saintly man. All of these books have been written from information gathered in archives and logically translated to paper in the writer's point of view.

However, no one has written a book based on testimonials from people who knew Father Damien personally and who were recipients of this love, generosity, compassion and teachings. In the book Father Damien...A Bit of Taro, A Piece of Fish, and A Glass of Water, Anwei and Henry Law have based their writings solely on the stories as told by the very people who for many years until his death shared their life on the Settlement of Kalaupapa with Father Damien. These stories have been brought to life by Anwei and Henry Law, stories that were silenced from time immemorial----until now.

The Laws have created a beautiful read with gripping photographs that bring witness accounts of people from another time to speak the truth of a simple man who came to Kalaupapa island to work with fellow humans, restoring their faith in humanity, dignity, provided counseling, and fulfilled the religious void so needed by residents in a leprosaria. The book is filled with words from past residents like Bernard Panikaia who said of Father Damien..."I think of Him as my North Star---He guides Me." Hours of work were spent reviewing oral histories in order to resurrect the beautiful journey of this saintly man and his infectious love.

Reviewer: Ymelda Beauchamp (former resident of the U.S.P.H.S. Hospital in Carville, Louisiana).

Congolese Physician and Humanitarian the Recipient of the 2008 Damien-Dutton Award for Leprosy Work

On November 5, 2009, Dr. Jacques Kongawi was presented with the Damien-Dutton Award in Greenville, South Carolina. Former award recipients include President John F. Kennedy, the first President to proclaim "World Leprosy Day", Mother Teresa and Stanley Stein, founder of The Star.

Dr. Kongawi works tirelessly, often in life-threatening situation, to treat people affected by leprosy in his native DR Congo, a country torn apart by war and a shattered economy. He and his health workers travel by motorbike, canoe, and foot to bring healing to people who might otherwise have spent their entire lives never seeing a "real" doctor.

The Damien-Dutton Society for Leprosy Aid is dedicated to the elimination of leprosy and raises funds for medical care, research, social and physical rehabilitation, and education. The society was named after Father Damien, a Belgian priest recently canonized for his care of persons affected by leprosy on the island of Molokai, Hawaii and Joseph Dutton, who assisted Father Damien and served on the island for 40 years.

The American Leprosy Mission (ALM) hosted the reception in South Carolina for Dr. Kongawi as he is ALM's Country representative for the DR Congo.

In the Sanctuary of Outcasts: A Memoir (Hardcover) by Neil White

Book review by Paul Mange Johansen

Neil White found himself, at age 33, in a special place at a special time. He witnessed first-hand one of the final years that Carville operated as a center for the care of people with HD. His perspective was that of a federal inmate, incarcerated at Carville for bank fraud from May, 1993 until April, 1994. While there he interviewed and befriended some of the residents, forming an especially strong emotional bond with "Ella Bounds." She, more than anybody else, opened his eyes and heart to the possibility that a person with a scarlet letter could live simply and happily with dignity.

Mr. White, a former newspaper and magazine editor, used his experiences with the people he met at Carville to produce his memoir, In the Sanctuary of Outcasts. The book falls neatly into two halves. The first describes in excruciating detail a man too driven by ambition, pride and a deep-seated need for public accolades and wealth that he could not see how his flagrantly illegal actions hurt everyone around him. After his wife filed for divorce and moved away with their two young children, Mr. White was consoled by Ella and began a personal transformation that develops throughout the second half of the book. In general, the book devotes more pages to the author's history and light anecdotes of other inmates than it does detailing the residents' stories and the meaningful lessons they have to teach.

By the end it is unclear just how deep or lasting this personal transformation will be. The author undermined his cause early on when, as a troubling form of escape, he decided to merely *pretend* to be an inmate while instead serving as an undercover journalist. He imagined the speech he would give about his courage and compassion after accepting a prestigious award for his work. Most disturbing is Mr. White's liberal, continual use of "the L word" despite an author's note in which he claims, "I wish the word *leper* were not in our vocabulary." For comedic effect, Mr. White included terms another inmate used to describe the residents before the author corrected him: "leopard" and "leprechaun."

Institutional barriers prevented Mr. White from seriously delving into "the secret world" of HD at Carville. He is to be commended for his initial efforts, which puzzled his fellow inmates. But I worry that overall this memoir may do more to reinforce than to dispel the lingering, inappropriate and hurtful stigma faced by people with HD.

The Carville Star's Nationale Directuer's Promenade Adventure – 2009 by George Willis

The Nationale Promenade Adventure ending the 2009 Carville Star year began in Gaston, North Carolina on Tuesday, September 8th, with my wife Joyce and two puppies in tow. The 700 mile trip would prove to be adventurous with the puppies because of eating on the road and trying to find hotel rooms which would allow pets, plus the frequent stops along the way for “walks” was challenging to say the least. To top this off, every square inch of our SUV was packed to the hilt with clothes, dog crates, snacks, Carville Star program material, and two thousand Carville Star pins.

After a semi-restful night in Shamokin Dam, PA, we finally arrived in Rochester, NY. Now the task was to find the hotel and convention center. After three times across the Genesee River and passing the small entrance to the Radisson hotel with its one “alley” three times, we finally found the entrance and the parking garage. Once settled into our room, it was time to ‘walk’ to find registration. This trip would be the first of many, many trips across the ‘skywalk’ from the hotel to the convention center.

Wednesday morning, the start of program meetings, came very quickly and early in the morning. After attending two very informative meetings prior to our Carville Star meeting, we finally met with over seventy Voyageurs and Dames present. The Carville Star activities for the Promenade were discussed, especially the distribution of Carville Star literature and the 2010 Carville Star pins. A new and appreciated event/activity by the New York Promenade/Convention Corporation was their placing tables and chairs in the registration area for each Nationale program. Our Carville Star section was well placed where we received a great deal of exposure. The ‘great space’ was instrumental in the distribution of much of the Carville Star material I had packed in my SUV and many bags of Carville Star pins were distributed as well. “Merci” to the thoughtfulness of the Promenade Corporation for thinking of this; not only did it assist the programs but also helped to get information on the various programs distributed and questions answered up front.

After an action-packed three days of meetings, campaigning, and awards recognitions, it was time for an ‘attitude adjustment’ and banquet fun. With everyone ‘gussied up’ in their finest threads, we were ready to feast. The evening meal and camaraderie was great and the time came for our keynote speaker, the 2009 Americanism Award Recipient.

The Honorable James B. Peake, MD, was selected because it is said “he is a soldier, physician, humanitarian, and statesman.” Following his graduation from West Point, James Peake was assigned to the 101st Airborne Division in Vietnam. During his service he was awarded a Silver Star and two Purple Hearts. While recovering from his wounds, he was accepted and attended Cornell University Medical College. Continuing his Army career after graduation, now Doctor James Peake became Surgeon General of the United States Army, and Chief Operating Officer of Project Hope. In December 2007, the United States Senate unanimously confirmed Dr. Peake as the Secretary of Veterans Affairs. Dr. James B. Peake was the first physician and the first military General to serve as VA Secretary. He stated he wanted to make the VA a veteran-oriented system where everyone comes together to treat the whole veteran. He started his career as a fighting soldier knowing casualties were imminent, not knowing that he would become one of the injured. But despite his injuries, he picked himself up by the bootstrap and became a distinguished man, a military officer, a veteran, and finally the Secretary of Veterans Affairs.

This is what our military men and women do – they are knocked down but they don’t stay down. Once they are down, they get up, adapt, overcome, and continue to make the world a better place to live. We, in the United States, are very fortunate to have individuals like Dr. Peake, the leaders in La Societe, and volunteers like you, that donate their monies and their lives for our Forty and Eight in order for our fellow veterans to have a better life for them and their families after so honorably defending our country against tyranny.

With this being my first Nationale Promenade as a Nationale Program Directeur, it was truly a rewarding experience and a more than busy week, with much accomplished for our Carville Star program.

As a final note, I want to thank all the Grand Voitures and Cabanes, individuals, and sponsors for the 2008-2009 support of the Carville Star program and for the donations sent for our ‘special projects’. All of your work and donations are used to improve our Carville Star program and to promote the STAR publication to put Hansen’s disease on the ‘forefront’ of our awareness so that all will know that “stigma hurts.”

STIGMA

By Sylvia Sullivan Villareal

The following is dedicated to all who have lived in grace and dignity with Hansen's disease. Mrs. Villareal's interpretation is not intended to convey all the complex nuances of stigma.

Stigma
feels like
a red welt imprinted on vulnerable flesh
the glare of harsh lights trained on intimate corners of our lives
a bone deep aching that can only be relieved by connection to another

sounds like
fine crystal being pulverized by a hammer
pounding footsteps of predator and prey, muffled cries of shame and pain when outdated, cruel beliefs separate and isolate us

smells like
the piles of stereotypes
the mildew of fear compounded by ignorance
mixed with the faint whiff of arrogance toward the unfortunate "other"

tastes like
salty tears cried alone
bile that rises when labels obscure and minimize our true selves
a cold lump of sorrow that we swallow today and then again, tomorrow

looks like
brief, furtive glances, others hostile
and unabashed, the hand too quickly withdrawn
the subtle wince at a thoughtless comment that abrades a tender spot

Stigma dissolves with
feelings of compassion flooding into those closed off chambers in our hearts

sounds of conversation breaking out among those too long without voices
the scent of fresh perspective rushing into a stifling and airless room
the taste of freedom to fill ourselves up on the truth of who we really are
the sight of human beings, all flawed and shining, arms open
beckoning each of us to our place in an ever widening circle.

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The Art of Learning and Educating Others

It is 6 a.m. on June 13, 2009 and we are at Hobby Airport in Houston, Texas. Our names are Jonathan Guajardo, Jairo Monasterio, and Jesus Zepeda from Horace Mann Junior High School in Baytown, Texas. We are 14 year old boys on our way to Washington, D.C. with our sponsors, Mrs. Ami Liggett and Ms. Suzy Ferrell. For us, this had been a yearlong event which has culminated in a once in a lifetime learning experience. We have been participating in the National History Day competition which is a nationwide program that encourages America's youth to travel back in time and learn of the important moments, people, and actions in history. We began our journey in our school library August of 2008 with the discovery of one man who helped to change the lives of people with Hansen's disease. We chose Father Damien because of his personal beliefs, his unselfish sacrifices, and his relative anonymity. Little did we know that this man who died in 1889 would be on the front webpage of Yahoo News on February 21, 2009! Our exhibit, "Father Damien: A Helping Hand, A Healing Heart," explained how a young Sacred Hearts priest chose to travel to Molokai and spend his entire life helping the Hawaiian people who were exiled there in the early 1800's. We were inspired by Father Damien's work and believed that his story needed to be shared.

We first learned of Father Damien in a book found in our school library. After our initial readings, we began our search for additional information. Through internet sources, we were able to find Father Chris Keahi, the Sacred Hearts Provincial of the Hawaiian Province. With the help of Father Keahi, we were able to further discover Father Damien's journey and his impact not only on the people of the Hawaiian islands, but on people throughout the world.

We learned that as a young man, Father Damien felt that he was called by God to serve his fellow man. After several years in servitude, he believed he was called again to move to Hawaii to help the leprosy hospital that was in existence. Although he originally expected to remain for a three month period, he strongly felt that he belonged on the island. He would stay and serve as a spiritual leader, doctor, builder, farmer, and friend until he died of leprosy at the age of 49. He never regretted his decision to stay; in fact, he believed he had led a happy life filled with servitude.

To present our finding, we decided to build our board to resemble the church where Father Damien spent the majority of his life, Saint Philomena. We knew that we wanted to include the people we interviewed because we believed they were important in the presentation of our project. Mrs. Audrey Toguchi spoke with us about her cancer journey and her miraculous healing. Her proven miracle was a major point in convincing the Vatican in Rome to declare Father Damien a Saint on October 11, 2009.

José Ramirez, Jr., a man who spent a large portion of his life at the national leprosarium in Carville, Louisiana, described his own story in dealing with Hansen's disease and his journeys to Molokai to share happy moments with his "brothers and sisters" who resided at Kalaupapa Settlement. Marian Matsu R.N., from Houston Hansen's clinic, explained the current status of Hansen's disease and people presently receiving treatment. Paul Knobloch, a man treated at the Houston clinic, met with us to describe his diagnosis and treatment. Mrs. Ivy Kahilhiwa, one of the last residents at Molokai, spoke to us about her life and Father Damien. Finally, we spoke to Father Vanderbroek, the Sacred Hearts Priest currently assigned to Molokai. Speak-



From Left: Jonathan Guajardo, Jairo Monasterio, and Jesus Zepeda. 8th grade students at Horace Mann Junior School competing in the National History Day Competition at the University of Maryland. This picture, part of the National Statuary Hall Collection, was taken at the Capitol in Washington D.C.



This exhibit placed 7th at the 2009 National History Day competition. With the assistance of Father Keahi, the boys were able to provide a pictorial display of Father Damien's life.

ing with all of these people allowed us to truly gain a deeper understanding of the people affected by Hansen's disease.

With this knowledge behind us, we had high hopes at winning at each level of the competition. At our school and regional competitions, we placed first in our category. At the state competition in Austin, Texas, we placed 2nd out of over 40 entries across the entire state. With our second place finish, we were so excited and our dreams of being on a plane to National History Day had come true. We would be eligible to compete against students across the entire nation.

During our five day stay we had many great experiences. We learned about the importance of team effort; the unique challenges of travel; the special history of our country; the aches and pains of walking when we are used to driving everywhere; the wonders of viewing the University of Maryland and Fort McKinley; the combination of fear and excitement of being interviewed by event judges on our exhibit; the special feeling of meeting our congressman and then seeing the marble statue of Father Damien at the Capitol; the joy of touring the White House; the exhilaration of receiving 7th place in this national competition; and the indescribable pleasure of being able to educate so many about Hansen's disease.

This remarkable journey on gaining so much knowledge would not have been possible without the support of so many, especially our two school sponsors and our wonderful parents and extended families.

Major NHDP Museum Acquisition By James Krahenbuhl, Director of NHDP

In June of 2009 the National Hansen's Disease Programs Museum was privileged to receive and place on permanent exhibit the Robert K. Myles leprosy currency collection. With the obvious experience and efficiency garnered from setting up displays at numerous numismatic conventions, Dr. Myles, a retired physician from Reno, Nevada, his wife Jean and daughter Lora carefully installed the exhibit in three beautiful glass cases which they also provided to the museum.



This currency collection represents tangible testimony to the psychosocial stigma of leprosy. Even in the first half of the 20th century the medical community was well aware that leprosy was not easily transmitted yet acquiesced to public fears of the disease with a policy of forced confinement in national leprosaria throughout the world. Many of these leprosaria developed self sustaining economies where currency was essential but interchange with the outside world was limited. Special leprosy currency was employed to satisfy the public ("...and prevent transmission to the outside world..."). From the collection it is easy to conclude that this unnecessary practice was carried out only in developing nations. Special currency was not employed at Carville but money exchanged with the outside was indeed "laundered" in boiling water and hung out to dry. Heat sterilization of all outgo-



ing mail, including the STAR, only ended as official policy in 1958.

The Myles collection was merged with an earlier collection of leprosy currency provided to the museum by James Archibald, allowing the display of both sides of certain coins. This exhibit is the finest leprosy currency collection in the world and will remain the centerpiece of the NHDP museum and a focal point for discussion of the leprosy stigma with visitors. We are extremely grateful to Dr. and Mrs. Myles for their generosity, friendship and support of the museum.

James L. Krahenbuhl, Ph.D.
Director, NHDP

The NHDP MUSEUM ROBERT K. MYLES LEPROSY CURRENCY COLLECTION

Lifetime collections of art or other items pose a problem as people reach the time of life when they need to make provision for their collections. All too often, dealers purchase cherished collections. Items are sold individually, which destroys the integrity and history of the collection. After a family discussion, I decided to donate my collection of numismatic leprosaria, coins, notes and associated items, to the National Hansen's Disease Museum. Leprosaria specialist, Jim Archibald, had earlier donated a small currency collection. Joining the two collections allows both obverse and reverse of several of the coins to be shown. Archibald has also donated an impressive postage collection. Both collections add to the history of an era in medicine and the treatment of people with a specific disease.

My interest in leprosy began when I learned of the "Leprosy Colony" that existed in Hawaii. Molokai and Father Damien were often topics of discussion as I was growing up in California. During medical school I saw one leprosy patient at Stanford Hospital, at a time when sulphones were being developed. During 40-plus years of Internal Medicine in Reno, Nevada, I had two patients with the disease. They were treated as regular patients on special medication.



After most of the leprosaria were closed in the 1950's, currency made for the use within "leprosy colonies" began to show up in the numismatic market. A patient, a coin dealer by profession, gave me a handful of "foreign coins," that he didn't have any use for. Among them were coins from Culion Island in the Philippine Islands. That gift began a long-time interest in the special currency. Most of the collection was purchased in the 1960's and 1970's, from dealers at numismatic conventions. At first, dealers who knew of my interest would call when they located "leper" coins or paper money. Because of the "stigma" of passing the disease on the exchange of money, they were eager to get rid of them. I recently spoke with one friend, a long time dealer, who said that he always washed the coins in alcohol as soon as he got them. As collectors focused in on the currency,

dealers found that they made more money on the currency at auction sales. I have exhibited the Culion Island and Palo Seco currency, along with post cards, Carville Mardi Gras tokens, and other items of interest, winning several awards at numismatic conventions.

Only five countries in the Western Hemisphere produced currency for use within their leprosarium, or lazaretos as the facilities are called in South America. Brazil, Colombia, Venezuela produced coins and notes. Culion Island in the Philippines and Palo Seco, Panama, run by the US Public Health Service, both produced coins. Culion Island produced paper

“script” during WWII. Carville and Kalaupapa used regulation U.S. currency, which was sterilized before it went “outside.” Carville minted colorful Mardi Gras tokens from 1982 to 1998.

The combined museum collection includes the story of “Pete the Pig,” with four small piggy banks made by the American Leprosy Society in the 1930’s, and two Father Damien medals from Hawaii, issued in 1995. These were also a gift to the museum by James Archibald. The Damien medals were issued in recognition of the first step of the journey to sainthood. Damien will be canonized as a saint in October 2009. Room has been left in the display for the 2009 sainthood medals.

Palo Seco, Panama is unique. When the United States Government entered into the contract to build the Panama Canal, the Panama Canal Zone was created. In the contract, Panama included a clause that forced the U.S. Government to become responsible for health care in the Zone. When the USPHS found leprosy in the area, they immediately created the isolated Palo Seco Leprosarium. In 1919, Palo Seco “tokens” were minted at the Philadelphia Mint. The same size as U.S. coins, the tokens were minted of aluminum instead of silver. The Palo Seco facility is still in use. However, the Panama Government and land developers are hotly contesting the very desirable piece of land on the Pacific side of the Panamanian Peninsula.

Culion Island in the Philippines also has an interesting history, with coins minted at the U.S. Mint in the Philippines. When the Philippines took over the mint, they stopped production of “leprosy money.” Paper money in the collection was issued “on special authority” as emergency money during the Japanese occupation in WWII. The “emergency” paper money collection is complete, including a rare 50/20 “print-over” note.

When medical treatment allowed Hansen’s Disease patients to re-enter society, use of leprosarium coins at Palo Seco and Culion Island were discontinued. The coins were recalled and destroyed, the notes recalled and burned. What has appeared in the numismatic market are items saved as curiosities by patients or staff. Leprosaria currency rarely appears on the market today, except when a collection is placed for sale.

Currency from South American lazaretos came on the market in the 1980’s. They are rarely found in the US. The ones I have been able to purchase enlarged the collection to include currency from the Western Hemisphere. Brazilian leprosaria coins are from the Colonia Santa Theresa and Santa Casa de Misericordia Lazaretos. Colombia lazareto coins circulated within the three State run facilities of Agua de Dios, Cano de Loro, and Contratacion. Venezuelan leprosaria coins are from two lazaretos: Maricaibo, which was renamed Isla de Providencia, and Cabo Blanco. Coins displayed show the three names. At one point, the Venezuelan Government recalled all of the coins, replacing them with paper notes. Four Cabo Blanco notes are included in the collection.

The last coins purchased for the collection, a rare set from Santa Casa de Misericordia in Brazil, was purchased in April 2009. The collection is a rare window on an era in the Western Hemisphere. According to Archibald, the collection is one of the most complete of its kind. Donor initials are found throughout the display as RKM or JEA. The combined collection is a rare window on an era in the Western Hemisphere. According to Archibald, the collection is the most complete of its kind. Donor initials are found throughout the display as RKM or JEA. Included in the collection are two books, one a signed copy of *The Leper Squint*, by Anthony Weymouth, dated 1938. The second book, the “Bible” of leprosaria, is McFadden, Grost and Marr’s *The Numismatics of Leprosy*, 1994, seen displayed in the accompanying photos.

My family and I are pleased to have the opportunity to add this collection of numismatic leprosaria to the National Hansen’s Museum exhibits. To have the collection available, as a reminder of an era of medical and human history, is of great importance as the memory of the leprosaria and lazaretos in the Western Hemisphere slowly disappear over time.

Robert K. Myles, M.D.
Reno, Nevada

Edited by: Jim Archibald, U.S. Coin Collecting Editor
Lora E. Myles, Esq.

Visit to Carville by Mr. Yohei Sasakawa

By James Krahenbuhl, Director of NHDP

In early October the National Hansen's Disease Programs (NHDP) was privileged to host a visit by Mr. Yohei Sasakawa, Chairman of the Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination. For over 40 years the Foundation has been closely involved with the global campaign to eliminate leprosy, working in co-operation with the World Health Organization, governments, international organizations and NGOs. The Foundation funded, between 1995 and 1999, free multi-drug therapy (MDT) for every leprosy-affected person in the world. Sixteen million people have been cured of the disease since MDT first became available in the 1980s.

In 2006, he established the Sasakawa-India Leprosy Foundation to assist the economic independence and social rehabilitation of leprosy-affected people in India—home to the world's largest population of people affected by Leprosy. Sasakawa's draft resolution for the "elimination of discrimination against persons affected by leprosy and their family members," was unanimously adopted by the UN Human Rights Council in June 2008. Since 2006 he has launched a series of global appeals to raise international awareness of the problem of discrimination against leprosy affected individuals. These appeals have been supported by world leaders, the leprosy affected people themselves, leading human rights and disability NGOs. The fourth Global Appeal was launched by faith leaders from Christianity, Islam, Judaism, Buddhism, and Hinduism and endorsed in January 2009.



His time in Baton Rouge was limited but Mr. Sasakawa was able to tour the NHDP research labs at Louisiana State University where he was given a briefing on research goals tied to prevention (vaccine) and early detection of leprosy, development of molecular tools to study transmission, basic research into the mechanisms of leprosy pathogenesis and development of the armadillo as a full model for human leprosy. He ended his day at the historical site at Carville, making a point to see the site on the Mississippi River where the first seven patients were put ashore in 1894 and visit the grave of Carville's patient #1. Mr. Sasakawa toured the NHDP museum where the exhibits and artifacts display the fascinating history of the National leprosarium. He was also able to visit with several of the 13 elderly residents, formerly patients, who still reside at Carville in space leased from the State of Louisiana. Mr. Simeon Peterson, shown in the picture, has been a resident at Carville since 1951. Mr. "Pete" works part time at the museum as our "ambassador" greeting and answering the queries of visitors.

This was Mr. Sasakawa's first visit to Carville and the NHDP staff was delighted to finally meet the man who has made his life's work the elimination of leprosy and an end to discrimination faced by tens of millions of leprosy-affected people around the world.

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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.

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