Pope Francis uses the term "Hansen's disease" during June 12, 2016 mass at Vatican City.

(Pictured - St. Peter's Square March 10, 2007)
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The purpose of The Star is to: 1) Promote an educated public opinion of Hansen’s disease, 2.) Furnish vocational rehabilitation for interested patients.

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

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June 12, 2016 was a day long sought by Stanley Stein and the editors of The STAR who followed him. For the first time in 2,000 years, a Pope had not referred to us as "lepers" or "L" word, nor a leprosy. Pope Francis referred to 40 of us from all over the world as "persons affected by Hansen's disease," and acknowledged our attendance at a first-of-its kind symposium in Vatican City. This unique event occurred during Sunday mass at St. Peter's Square as we sat next to the altar following communion. I was proud to be the only person affected by Hansen's disease, accompanied by my wife, from the USA.

The day was shrouded in rain until the moment that Pope Francis emerged from the basilica, with sun shining on his white robe. The day brought an end to Pope Francis' description of Vatican bureaucracy, the abuse of children by priests, and sin as "a leprosy." He had also previously used the "L" word as an analogy to "all things bad." Leprosy is the only disease mentioned in the Bible and the only illness identifying us by the disease. Those of us affected refuse to be identified by such.

The journey to St. Peter's Square started over 4,000 years ago when persons affected by Hansen's disease were often buried in segregated graves. These 40 centuries also represent over 100 generations of my brothers and sisters buried separately from the rest of the community. This practice did not start to diminish until the mid-1950's. They were labeled "the living dead" and then disrobed of their dignity after death.

By scrutinizing the Bible on references related to leprosy one can easily find rules that are counter to The Ten Commandments. For example, persons with leprosy are forbidden to travel on a public road, forbidden to enter a church, forbidden to drink from a common fountain, forbidden to be intimate with anyone other than another with the disease, and so forth. The 40 of us who traveled to Vatican City felt no shame in having had violated the commandments related to Hansen's disease.

The symposium was attended by 300 individuals from 45 different countries. It was co-hosted by The Pontifical Council for Health Care Workers and The Nippon Foundation from Japan. Mr. Sasakawa, UN Goodwill Ambassador for the Elimination of Leprosy and Chair of The Nippon Foundation, met separately with Pope Francis prior to the start of the symposium and advocated for the elimination of the "L" word. After listening to so many stories about the denial of human rights, outrageous labeling and ostracism, Monsignor Jean-Marie Mupendawata from the D.R. Congo and co-chair of the symposium made the following observation, "It is unfortunate that the many rules set forth by many religions have been created into laws by governments and personally apologize for these
rules against humanity." I shared with the symposium attendees that knowledge about Hansen's disease is powerful; however, ignorance about this disease is even more powerful.

Being in Vatican City during the Jubilee Year of Mercy meant for me coming full circle on the journey with Hansen's disease. Forty-eight years ago I was diagnosed with this misunderstood disease at Mercy Hospital in Laredo, Texas. Even though my family, girlfriend and friends thought that the diagnosis meant upcoming death, the Sisters of Mercy nervously tried to reassure all that this was not so.

Nervously because my mother immediately recognized the usual connection to leprosy.......sin. She believed, and shared with me in inconsolable tears, that God was punishing her, through me, for her sins. I could not understand why God was being so cruel to my saintly mother. This cruelty included her witnessing a priest administer the last rites to me prior to being placed inside a hearse en route to seven years at the national leprosarium in Carville, Louisiana. My mother, Rosa, felt great sadness for decades asking the question WHY? like a female Barabbas. She asked God for "mercy" in allowing me to me be cured. Fortunately I was treated with an experimental medical regimen at the time, which has now become the standard care, and loved unconditionally by my mother. Pope Francis said during mass that the "best medicine for any illness is love."

My journey to Vatican City to present on "Stigma and Toxic Imagery" started on June 4, 2016. On this date Cardinal DiNardo of the Galveston-Houston Diocese offered his blessing to me and my wife for safe travel to Rome, and a successful first-of-its kind symposium.

The excitement of attending such a special event in Vatican City concluded with renewed energy with recommendations. Some of these included: endorsement of the United Nations approved guidelines to eliminate discrimination against persons affected by Hansen's disease; increase in expertise in the treatment of this disease and corresponding research; increased empowerment of persons affected; elimination of discriminatory laws throughout the world; on-going efforts to eliminate stigma; and adoption of the motto "One new case of Hansen's disease is one too many."

The day after the symposium the 40 persons affected met with members of the United Nations Advisory Committee on Human Rights to respond to questions being posed to all nations on issues related to Hansen's disease and basic human rights. The meeting was led by the committee's chair, Dr. Okafor, and he reassured all that the focus of the symposium would not be lost as a report is prepared for the United Nations. The group of 40 departed Italy with a commitment to continue the fight against labeling, discrimination and stigma typically aimed at persons affected by Hansen's disease, and with a dream to have the symposium become an annual event.
My Friend Johnny Harmon
By James Krahenbuhl, Ph.D., Director NHDP (retired)

I first met my friend Johnny P. Harmon at the Carville Centennial Celebration held at the G W Long Hansen’s Disease Center in 1994. Johnny made a short presentation during which he presented to the center’s director Dr. Jacobson, his oil painting representing the arrival of the first 7 patients in 1894 on a barge from New Orleans. Johnny had no formal education beyond high school but was a skilled artist and had a love of anything aeronautical, especially WWII aircraft and a gift for mathematics. As a young man he had worked for the Texas Highway Department for several years as a surveyor and draftsman before Hansen’s disease (HD) forced his confinement to Carville in 1936 where he joined his brother Elmo. I am certain that if HD had not interfered Johnny would have graduated from Texas A and M and had a fulfilling career with NASA.

At Carville he married Louise Anne, the love of his life and focused his talents on photography with a little shop that served the needs of the patients. His talents were recognized by Stanley Stein and he became the Star’s official photographer and resident cartoonist. He worked only in black and white using his favorite Rolliflex or a large format Speed Graphic camera. Dozens of his photos grace the NHDP Museum and there are hundreds in the files. Few are mere snapshots. Shots of visitors and patient activities are carefully composed to exploit existing lighting conditions. His shots of the grounds and unique architecture of Carville are spectacular. Johnny always shot for sharpness and maximum depth of field claiming, “you could see the stitches on their britches.” He often used a red filter to enhance the subtle tones of gray comprised in the huge cumulus clouds that boil up from the Gulf in late afternoon. Johnny’s cartoons could be found in the Star from 1945 until ~1954 and each was a work of art. Most of his cartoons incorporated the unique architecture of Carville. He had the gift of mechanical perspective and the depth of field and detail in the cartoons is amazing.

My friendship with Johnny dates to 1995 when I was Chief of the Laboratory Research Branch. He inserted a math quiz in the weekly patient newsletter. It was a typical high school algebraic word problem, the kind that vexed me when I was 17. I sent him my solution and introduced myself. He responded with the correct answer, an application of the Pythagorean Theorem, and added bluntly, “You may be a hot shot researcher but you don’t know a damn thing about math!” I had to meet this guy.
I invited him and any patients who wanted to accompany him to take a field trip to the lab at LSU for lunch, a tour of the labs and a presentation of the goals and research approach of our LRB investigators. Johnny showed up with about twenty patients and sat in the front row during my presentation. At one point I showed a cartoon extracted from a 1946 *Star* that humorously depicted a leopard losing its spots as the “Miracle at Carville,” the discovery of Promin as the first effective drug against the leprosy bacillus. The artist had signed the cartoon, “J. P. Harris.” Johnny piped up, “That’s my cartoon. That’s the pseudonym I chose when I entered Carville.” Johnny understood the concepts of the leprosy clinical spectrum and that we were doing basic biomedical research on the disease; virtually nothing we were studying would affect the course of his disease or, likely, that of anyone at Carville. After taking his photograph peering through our electron microscope at his nemesis, the leprosy bacillus magnified 100,000x, We parted friends for life.

Besides acquiring a treasured personal friend the LRB could not have recruited a more loyal, vocal and proactive supporter. He never hesitated to write senators, congressmen, the Governor, New Orleans and Baton Rouge newspapers, The Washington Post, etc., to support us in a number of federal budgetary and downsizing crises. In 1999 he strongly resisted the stipend plan and the relocation of the program and chronically ill patients to Baton Rouge but deep down Johnny realized it was a necessary move for the program, his elderly fellow patients and, ultimately, himself.

When he was finally admitted to the chronic care facility leased at Summit Hospital in Baton Rouge Johnny’s first act of patient advocacy was to convincingly point out to the CEO that the food delivered daily was cold. He sent him compelling evidence, a digital photograph of that morning’s breakfast, two fried eggs with runny yolks plopped on top of a local lumber yard thermometer that read 55F. Heated food carts showed up soon thereafter.

My friend and I had coffee, breakfast or lunch weekly. I pumped him relentlessly for his experiences as a patient at historical Carville and a member of the “Greatest Generation.” We took a number of field trips to the D-Day Museum, the Stennis Space Center, the USS Kidd Museum. We even visited with the pilots of the Confederate Air Force at the Baton Rouge airport where he got to kick the tires of a B-17 and a B-24 bomber.

Johnny P. Harmon died in 2002, aged 90. I miss him.
On March 18, 2016, 74 year old Hilarion "Laloy" Guia relocated to Heaven to join his parents, Gil Guia and Maria Magbuhos, and grandmother Francisca Gonzales. His grandmother became his life after his parents died soon after he was diagnosed with Hansen's disease at age three.

"Laloy" was sent to Culion, "The Isle of the Living Dead" and was able to impact its change to "Paradise Regained." He was able to do this with his eloquence, intelligence, compassion, persuasive skills and diplomacy.

This beautiful man became the most powerful figure at Culion, the island reserved for persons affected by leprosy in the Philippines. He succeeded because of the mentorship he received at home; his education in segregated schools; at the Holy Rosary College where he received a Bachelor of Science degree in Education; teacher and later President of the Faculty at his alma mater the Loyola College of Culion; the introduction of MDT (Multiple Drug Therapy) in 1985 to the residents of Culion; leader of civic and governmental organizations; and campaign manager for a national Senator. During this journey he married Rosalinda and served as foster parents to seven children, four who were orphans of persons who died from untreated and advanced stages of Hansen's disease.

As a result of his active participation in the world of politics, he received the support of many elected officials to change the status of Culion. In 1992, the Philippine Congress enacted the Republic Act 7193, transforming Culion from a sanatorium to a regular municipality. This long sought action, led by "Laloy," resulted in an election of the first mayor of Culion in 1995. As Mayor of Culion, "Laloy" positively changed the general health of its citizens and greatly improved the infrastructure of the community.

After leaving office he continued his advocacy on behalf of persons affected by Hansen's disease. He was interviewed by the international media, coordinated the Centennial Celebration of Culion and in 2005 became the first Philippine President of Integration, Dignity and Economic Advancement (IDEA), an international organization of persons affected by Hansen's disease.

"Laloy" was and continues to be an inspiration to the millions throughout the world affected by Hansen's disease.

The ILEP Advisory Panel of Persons Affected by Hansen’s Disease
By Mathias Duck

ILEP is an international federation of 14 anti-leprosy NGOs, working in 63 countries worldwide, supporting a technical commission of world experts on Hansen’s disease. ILEP was born out of a need to co-ordinate the work of anti-leprosy organizations supporting activities in leprosy endemic countries, to prevent overlap and avoid duplication in funding.

The ILEP’s strategic plan 2015-18 acknowledges the need for ILEP to work closer with people affected by leprosy to guide its policies, governance and strategy. This would be in order to strengthen our advocacy work; acknowledge the demand of many persons with disabilities and improve decision-making in ILEP.

To this end ILEP has decided to work with a Panel of Women and Men Affected by Leprosy to provide recommendations for closer collaboration going forward. The panel, which is advising ILEP in regards to strategies and policies, was established in the fall of 2015. The members of the panel are Rachna Kumari from India, Kofi Nyarko from Ghana, José Ramirez from the USA and Mathias Duck from Paraguay. The panel met in Paris in October of 2015 when the panel was officially established. In 2016 the panel has met in Geneva in March and is scheduled to meet in Bern in October.

The purpose of the Panel had been established by ILEP as to:

a) Work with ILEP staff and governance to understand ILEPs work better.
b) Consult with others affected by leprosy to gather their views on how ILEP can improve its collaboration with people affected in order to improve the impact of its policy and programmatic work.
c) Make a series of practical recommendations to ILEPs Members Assembly in 2016 for charting a more permanent way forward of impactful collaboration.

The panel was set to convene in October 2015, work with ILEP staff and governance during 2015 and 2016 and reconvene at the end of 2016 to present a series of recommendations to enhance the collaboration going forward.

Additionally, the panel has proposed the implementation of a policy, which guides ILEP and ILEP members with regards to images and language. This new policy will provide guidelines for a way of communication that is respectful of the dignity of persons affected by Hansen’s disease.

The panel is also supporting a research project about the experience of stigma among persons affected by Hansen’s disease. This investigation aims at collecting data from 10-15 affected persons from at least 25 of the most endemic countries. The findings of this research project will be presented at the International Leprosy Congress in September 2016 in Beijing.

At this point, the panel is working on the recommendations regarding the future of the panel. These recommendations are going to be presented to the members assembly of ILEP at the meeting in October 2016 in Bern, Switzerland.

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Obituary: Robert Jacobson, M.D., Ph.D.
By James L. Krahenbuhl, Ph.D.

Dr. Robert R. Jacobson, age 83, died in Woodstock, GA on December 1, 2015. Dr. Jacobson, known to his friends and colleagues as “Jake,” was a physician and international authority on clinical leprosy. Dr. Jacobson received his undergraduate degree in chemistry from the University of Minnesota, his Ph.D. in organic chemistry from the University of Wisconsin and his M.D. from the University of Minnesota.

As a commissioned officer in the U.S. Public Health Service’s (U.S.P.H.S.) commissioned corps, he practiced at the Gillis W. Long Hansen’s Disease Center in Carville, LA for 34 years where he served as a staff physician, becoming Chief of the Clinical Branch and rising to Director of the Center. He was an outstanding physician beloved by the hundreds of patients at Carville for his caring expertise and quiet gentle manner. During his career he carried out long term toxicity studies on clofazamine and pioneered work on Rifampin resistance in leprosy, fostering the introduction of this potent bactericidal component into the multi-drug therapy regimen for the disease. He was a member of the World Health Organization THELEP scientific working group and traveled extensively to leprosy endemic areas of the world as a researcher and consultant for WHO, foreign governments and non-government organizations to train and help treat the disease worldwide. Dr. Jacobson loved his work and received numerous commendations from the U.S.P.H.S., including the Meritorious Service, and Distinguished Service Medals.

Jake possessed a quiet humility that spoke volumes. He was the Director, the Boss. His desk in the mansion would have accommodated a helicopter landing. Others in a position like his would have used that massive desk to intimidate subordinates. Yet on every visit I made to him as Chief of the Laboratory Research Branch he stood, greeted me and ushered me to a small round oak table in the corner where we could discuss the business at hand.

Jake was a cautious and evidence-based researcher. When the 1991 WHO Assembly targeted elimination of leprosy by the year 2000 he was a strong but unsuccessful advocate for reduction in incidence of new cases as a marker of success rather than reduced prevalence of existing cases. As Director of the Center in the 1990s he oversaw the relocation of the Laboratory Research Branch (LRB) from its outmoded labs at Carville to modern facilities in the nearby Louisiana State University School of Veterinary Medicine. When a budget slashing Congress targeted basic biomedical research as non-essential to patient care at Carville Jake vigorously supported efforts to maintain the LRB, its multidisciplinary group of investigators and its unique research resources as vital to the Center’s mission.

Jake didn’t seek the office of Director. It was thrust on him. He was an obvious choice when the previous Director was essentially dismissed. Jake’s life was in clinical disease and the Clinical Branch. Each day he made the quarter mile walk from the Director’s Obituary: Robert Jacobson, M.D., Ph.D. office to the Clinical Branch at least twice. It was good exercise of course but, more importantly, it allowed him to distance himself from intramural administrative problems and bureaucratic hassles with HQ. When he took the job as head man he knew what was inevitable; the closure of Carville and relocation of the program. Before retiring in 1999, he oversaw the relocation of the clinical, rehabilitation and training programs from the 105 year old historic site at Carville to a medical center campus in Baton Rouge, where it became the National Hansen’s Disease Programs (NHDP). The remaining 120 elderly residents received either a stipend, were moved to the chronic care facility at NHDP or were permitted to remain under assisted living conditions at Carville, now operated by the state of Louisiana. The change was dictated by severe budget constraints and assured the continuance of the program at a new site but it had to be a bittersweet necessity to a man who had spent his entire medical career at Carville. In his retirement years Dr. Jacobson continued to travel, lecture and share his vast knowledge of clinical leprosy.
The International Symposium on the topic, “Towards Holistic Care for People with Hansen’s Disease, Respectful of Their Dignity,” was jointly organized for June 9 to 10, 2016, at Vatican City by the Pontifical Council for Health Care Workers, the Good Samaritan Foundation and the Nippon Foundation in cooperation with the Fondation Raoul Follereau, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation. These Conclusions and Recommendations were presented at the end of the two-day symposium and were approved in principle by the organizers and the participants who were present.

Note: While the terms “Hansen’s disease” and “leprosy” are used interchangeably in this document, in some countries the preferred term is Hansen’s disease.

Conclusions:

1. Every new case of Hansen’s disease is one case too many. It has been observed that new cases of Hansen’s disease are on the decrease and we should be very happy about this. But this decrease, which is in itself positive, could have resulted from a decline in case-finding activities and reduced community awareness. The increase in the rate of disabilities in new cases detected seems to support this explanation. Therefore, it is essential to aim at early detection. This applies to all new cases, but particularly to child cases. The WHO’s Global Leprosy Strategy 2016-2020 is moving in this direction. A second cause for concern comes from the substantial risk of partly losing the expertise that has been accumulated over recent decades by leprosy experts, medical doctors and health workers in relation to Hansen’s disease. Grants for study and training may be needed for service providers and caretakers including persons affected by the disease. Here, the principle, “Nothing about us without us” should be respected, and this is an important way of fighting against the stigma that is associated with Hansen’s disease. A number of valuable recommendations in the presentations concerned methods to improve early diagnosis and promote the social integration of persons affected by leprosy. Public and private institutions should work in close cooperation with health authorities in each country to provide medical and health personnel with basic education about leprosy in order to strengthen leprosy programs within the framework of general health services. Efforts should be made to reintegrate communities of persons affected by leprosy into society. The message that leprosy is curable and can be treated while the patient continues to live at home should be emphasized.

2. Every case of stigma and social exclusion is one case too many. Stigma is often associated with a religious vision of life and it would be advisable to revise this belief. In reality, stigma has been linked from the earliest times with fear of a disease that cannot be defeated. Biblical texts of the Old Testament themselves record a practice of exclusion that was present in Egyptian, Assyrian-Babylonian and Canaanite cultures during the second millennium before Christ. The same fear is to be found in non-Christian and non-religious contexts. The teaching of Christ in the New Testament, first of all, breaks, with great clarity, the connection between illness and sin (John 9:2-3). Secondly, Jesus Christ touches people with leprosy, enters into contact with a sick person without any fear of contagion or impurity, and heals and reintegrates people into the community. Even more, he himself accepts being treated as if he had leprosy. The example of Christ has often not been followed—this neglect enables us to understand that it is easier to eliminate the disease at a medical level than the social prejudice that surrounds it. In this sense, it is absolutely necessary that we place the human being at the centre of all medical activity, rather
It is the teaching of Christ which has led Christians, especially over the last two centuries, to develop a high level of care and treatment for people with Hansen’s disease. This took place even before pharmacological therapies were available, when care involved accepting and rescuing people and ending their state of abandonment. There is no need to recall here the giants of charity who were dedicated to this service. Today, as well, the Catholic Church remains strongly committed in almost all countries where the disease is found, to providing medical and humanistic care. Here a pathway opens up of cooperation with religious communities of other faiths and with all men and women of good will. It is the shared opinion of experts who work in the field of Hansen’s disease that the elimination of the stigma attached to leprosy requires an important work of education that must involve all social groups and in particular religious communities because they promote respect for human dignity throughout the world.

3. *Every law that discriminates against people affected by Hansen’s disease is one law too many.* Following intensive work, the General Assembly of the United Nations in December 2010 adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members, accompanied by ‘Principles and Guidelines’. The resolution and ‘Principles and Guidelines’ constitute a *milestone in the upholding of the human rights of persons affected by Hansen’s disease.* One must take into account that for every person with the disease, his or her family members and even relatives may also be ostracized due to the stigma attached to leprosy, resulting in a serious violation of fundamental human rights. An enormous amount of work still has to be done by governments and social and religious institutions to ensure that these ‘Principles and Guidelines’ are fully implemented.

*Unfortunately, various forms of discrimination continue to exist in many parts of the world which bear upon all spheres of life: schools, workplaces, social groups, public places, religious centres, restaurants, hotels, trains and other means of transport. Especially grave are the violations of the rights of persons affected by leprosy in the field of education, work, and marriage. The necessity to repeal discriminatory laws that impede fundamental human rights is very urgent and can no longer be postponed.*

Implementation of the ‘Principles and Guidelines’ requires constant work involving the sensitisation of governments and societies. To this end, in 2012 the Nippon Foundation created a working group (the International Working Group, hereafter IWG), which *had the aim of assisting the process of implementation of the ‘Principles and Guidelines’*. The IWG prepared “Suggested Framework for National Plans of Action” for States to use in their own domestic contexts.

The IWG came to the conclusion that the ‘Principles and Guidelines’ were more likely to be effective if States were called upon to *undertake specific ways of implementing them*, which could then be brought to the attention of various governmental offices and communicated to relevant UN bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions. To this end, the IWG recommended *the institution of a follow-up mechanism* at an international level which would have the mandate to follow up the actions of States and other stakeholders, drawing upon the experience of Special Rapporteurs on various topics of human rights appointed by the United Nations Human Rights Council, or committees of experts which monitor the implementation of international human rights treaties and conventions. This follow-up work must not be neglected, otherwise there will be no perception of progress or steps back.

Accordingly, in the Resolution adopted by the UN Human Rights Council on 2 July 2015, the UN Human Rights Council Advisory Committee is requested to submit a report containing practical suggestions for the wider dissemination and more effective implementation of the ‘Principles and Guidelines’ at the 35th session of the United Nations Human Rights Council in June 2017.

The IWG has observed, in particular, the need for civil society and religious communities to use dignified terminology when speaking about Hansen’s disease. It has been observed that the old perceptions of leprosy continue to be reinforced by inappropriate language. The offensive term ‘leper’ as a description of someone with leprosy evokes a marginalised person, a sinner, or a person who is rejected by other people for moral or social reasons. This terminology contributes to discrimination
against persons affected by leprosy and even discourages those who need treatment from seeking help. The IWG has thus in-
vited religious leaders and their communities to reflect upon the best ways of expressing themselves in language that is able to
transmit respect for persons affected by leprosy. Awareness-raising activities at the global level should make full use of new
media to inform people about advances in treatment of leprosy and the fact that people who are under treatment or have com-
pleted treatment are not infectious. It is important that this information is available even in countries where leprosy is not an
issue, in order to eliminate the myths surrounding this disease.

Final Recommendations

Two Introductory Points

1. Persons affected by Hansen’s disease must be seen as the main actors in the fight against this disease and the dis-
   crimination it causes. This involvement is a powerful instrument for the recognition of their equal dignity and rights for social
   inclusion, and for the breaking of the stigma attached to them. This point applies to all of the recommendations listed below.

2. The use of discriminatory language that reinforces stigma must cease, in particular, use of the term ‘leper’ and its
   equivalent in other languages. This term is offensive for the reasons stated above and also because it defines a person by his or
   her illness. Use of the term “leprosy” in a metaphorical sense should be avoided.

Five Recommendations

1. Given their important role in their respective communities of believers, the leaders of all religions—and this is an
   important and urgent matter—should, in their teachings, writings and speeches, contribute to the elimination of discrimination
   against persons affected by leprosy by spreading awareness that leprosy is curable and stressing that there is no reason to dis-
   criminate against anyone affected by leprosy or members of their families.

2. States and governments should be encouraged to make great efforts to implement the ‘Principles and Guidelines’
   accompanying the resolution adopted by the General Assembly of the United Nations in 2010 on Elimination of discrimina-
   tion against persons affected by leprosy and their family members. These ‘Principles and Guidelines’ must be fully imple-
   mented, otherwise they will remain just empty proclamations.

3. There should be a modification or abolition of all laws and regulations that discriminate against persons affected by
   leprosy. Policies relating to family, work, schools, or any other area which directly or indirectly discriminate against persons
   affected by leprosy must also be changed, recognising that no one must be discriminated against because of the fact that he or
   she has, or once had, leprosy.

4. There is a need for further scientific research to develop new medical tools to prevent and treat leprosy and its com-
   plications, and to achieve better diagnostic methods.

5. In order to achieve a world free of leprosy and the discrimination it causes, the efforts of all the Churches, religious
   communities, international organizations, governments, major foundations, NGOs, and associations of persons affected by
   leprosy which have hitherto contributed to the fight against this disease should be unified and joint plans of cooperation
   should be developed.
BEND IN THE RIVER: Louisiana’s Secret People.
By Tonya Hays

Where could we find a southern story that would engage us and intrigue us? Something we could work on for months as we created a piece of theatre that would travel to the Edinburgh Fringe Festival in August of 2016? A story that would challenge all involved to transform and transcend conventional mores and inspire and empower change?

The answer to these questions came in the form of an article on Trip Advisor about the National Hansen’s Disease Museum in Carville, Louisiana. I immediately sent the link to my writing partner and he was as excited as I was. Seven months ago we drove down to Carville and embraced the stories of the patients living with a disease long associated with stigma and sin. These patients, in spite of everything, and because of the dedication of the Daughters of Charity and medical pioneers gave a miracle to the world, the cure for leprosy.

After further research and several drafts, the play, Bend in the River: Louisiana’s Secret People, has been accepted by the prestigious Edinburgh Fringe Festival. In addition, the script was selected by the Orphange, a new play development lab through CoLAB Arts and has had readings in New Brunswick, New Jersey and at Theatre 167 in New York City. The response has been overwhelming. People want to know more about the isolated, microcosm of the world in a bend of the Mississippi River that was US Marine Hospital 66.

The creation of this piece is a labor of love. The challenge from the beginning has been, which stories to tell? We read several books, articles, Star excerpts and transcribed letters from the Daughters of Charity. And the many phone calls and emails exchanged with Elizabeth Schexnyder have helped provide answers to all of the questions we discovered during the writing process. The result is a script interwoven with American roots music featuring composite characters based on various patients and Daughters of Charity, as well as real people, Dr. Guy Henry Faget and Stanley Stein.

More than anything the play is a story of hope, sacrifice and devotion as the residents of Carville fought for and believed in a cure and educated the world on this misunderstood disease. What we can learn from Carville is that fear and ignorance give birth to cruelty, prejudice and intolerance. Carville can teach us not to make the same mistakes again but to strive to understand and empathize with others.

The dedicated cast and crew of Bend in the River will travel to Edinburgh this August. We are all honored and excited to bring this story to the largest Fringe Festival in the world.

The play will have preview performances, July 1 -3 in Gulfport, MS before it travels to Edinburgh in August. In November it will be restaged at the Lynn Meadows Discovery Center November 11-13.

For more details please contact Tonya Hays at tshays777@gmail.com and or Dustin Ballard at dballard17@gmail.com. And if you would like to help support the production, you can find our fundraising page here. https://www.facebook.com/bendintheriverplay/
Imagine that you have stumbled upon a family secret, a relative in exile that no one has ever spoken of. Intrigued, you meet that relative, a Portuguese cousin, and spend the next seventeen years, until her death, getting to know the circumstances of her life, her struggles, and her quiet achievements. Such was the case when I met Olivia Robello Breitha in December, 1989, on Moloka'i’s remote Kalaupapa peninsula. Some thirty-six years my senior, Olivia had been diagnosed with leprosy at Honolulu’s Kalihi Hospital in 1934, when she was 18. From that moment on she became parolee #3306 of the Hawaii State Department of Health.

As someone born and raised in Hawaii, I was thirty-seven when I first learned about Olivia from my mother. Like her first cousin, Lydia Marie Silva was born on the Hawaiian island of Kauai to Portuguese immigrant parents. They both grew up in a tight-knit, hardworking community where family pride and the magnetic pull of assimilation often clashed. People kept anything potentially embarrassing locked tightly in the closet. If word ever got out that someone in the family had contracted such a dreaded disease as leprosy it would have a serious effect on their social standing, the way they were treated at work, at school, even in church.

By the time I met Olivia the antiquated rules surrounding “the separation sickness” had largely vanished. In the 17 years that we were able to share, this tough, razor-witted lady taught me much about humanity in all its forms. She was a living witness to wrenching public policy decisions going back more than one hundred and fifty years, decisions that forever altered people’s lives and sent them to a place where few expected to emerge.

The inspiration to write “Shipment Day”, set in Honolulu between 1934 and 1937, came from a story Olivia told me a number of times. Sitting in her living room, the moonlit cliffs of Kalaupapa beside us, Olivia recounted what her last few days at Kalihi Hospital were really like, before being shipped to Kalaupapa. It was a tale that never left me. She told it to me several times, months and years apart, not because she’d forgotten having shared it. Maybe it was because she needed to keep getting it out in the open after more than forty years inside.

So, eight years after her death in 2006, I sat down to write of this startling episode in a young girl’s life. I knew I was taking on something bigger than myself, and something that brought Olivia much pain in remembering. But the incidents she shared with me were too powerful, too resonant to ignore. The play begins with lights coming up on a young woman of twenty-one. She's strong-looking, pretty even without makeup, a good Portuguese-American girl of modest means and high ideals. There is a bandage on her right forearm.

OLIVIA
In June of 1937 I received bad news. I mean really bad. I was handed a letter that killed any hope I had of ever getting well.

HOSPITAL OFFICIAL
Treatment is no longer of any benefit to you. This is to notify you that on Wednesday, June 30, 1937 you are being sent to live on Moloka'i, in Kalaupapa.
OLIVIA
Kalaupapa seemed to me like it was the end of the world, the very end. I was so scared. I tried to be cheerful in public, especially in front of my family. In the privacy of my hospital room my pillow was soaked with tears. My parents were heartbroken. They wondered if they would see me ever again. My mother tried hard not to cry but I could see the helplessness in her eyes.

“Shipment Day” goes on to show Olivia's experiences from the day of her diagnosis to her confinement in Kalihi Hospital to the day before her shipment to Kalaupapa, where she would spend the next seventy years of her life, until her death at the age of ninety.

After first developing the play at the Road Theatre in Los Angeles in late 2015, it was exciting to bring Olivia’s story back home, where it was selected by Play-builders of Hawaii for their 2016 New Play Festival. After four rehearsals the cast of local actors, headed by Kuulei Shafee as Olivia, did a staged reading on April 4, 2016 at the renowned Kumu Kahua Theatre in downtown Honolulu. They captivated the audience by bringing my cousin’s harrowing story to life. Writing and directing “Shipment Day”, which received the Festival’s Best Play, Best Actress and Best Actor awards, has allowed me to explore the compelling threads of my own family’s history. As I expand the play to full length, I look forward to sharing the secrets that lay hidden there, waiting to be uncovered.

(To learn more about “Shipment Day” and about Lorenzo DeStefano’s memoir, “Visitations – Finding a Secret Relative in Modern-Day Hawai‘i”, please visit www.shipmentdayplay.com www.visitationsmemoir.com

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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 Société 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 supports organizations at both local and national levels. To promote Americanism at both local and child welfare programs, provides aid to veterans and funds national nursing scholarship programs, the Forty & Eight raises funds and supports not only The Star, but also organizations dedicated to the needs of their fellowman.

Although the society’s roots were planted in 1920, the Forty & Eight continues to thrive.

Hansen’s disease (The Society of 40 Men and 8 Horses)

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