The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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DR. MARGARET BRAND

"My mother considered it one of the highest privileges of her life to serve the community of Carville."
—Pauline Brand Nelson

CONTENTS

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Stanley Stein
Founder - Editor, 1941 - 1967

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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Unique and Precious

By Pauline Brand Nelson

Some readers of this magazine will have learned already of the passing, at age 95, of my mother, Dr. Margaret Brand, on November 17, 2014. A memorial service was held in Seattle in January, and we were glad to see many old friends there, including former NHDC resident Ymelda Beauchamp, and others from the American Leprosy Mission.

Margaret had been living in the Seattle area since 1988, the year she and my father (Dr. Paul Brand) retired from the hospital at Carville. They had worked there for 22 years, enjoying life in that remarkable community so very much. Margaret spoke often of dear Carville friends, and we were all glad that, with the help of Dr. Ron and Mima Matthews, she had been able to make one last trip back in 2012.

It's astonishing to realize that Margaret outlived Paul by eleven years, because one always thought of them together. Paul's death in 2003 was an unexpected and painful blow for her, and initially she just longed for the day when she could be reunited with him. But if you knew Margaret you will not be surprised to learn that within a few months, she was once again living life with joy and enthusiasm. She traveled widely, always educating and advocating for a greater understanding of HD. She wrote her autobiography, dove into life at her retirement community, and of course played her violin every week, even while an injury required her to wear a neck brace. I think she was never happier than when making music with friends.

I was reminded of that during my visit to Carville in April of this year. While doing research in the Hansen's Disease Museum I was lucky enough to see video of a Mexican Independence Day celebration that Mum had taken part in. There she was, playing violin with the band. I loved seeing her movements again, so familiar to me, and so missed: the tapping foot, the dip of her chin to the instrument, the flash of her smile. Then I saw her touch a fellow musician's shoulder in a light, affectionate gesture, and it brought sudden tears to my eyes.

It felt so appropriate that I should glimpse that moment while visiting the very place where she gave and received such gestures of friendship so often. It reminded me of what was said at her memorial service, that even more than her skill as a physician, what Dr. Margaret really offered people was love. Her gift was to remind every person she met – whether a colleague, a patient, or a stranger on a plane – that they were unique and precious.

My mother considered it one of the highest privileges of her life to serve the community at Carville. I know she would want me to thank everyone who knew her then, for those extraordinary years together…and that she would also want me to remind you, dear reader, whoever you are, that *you* are a precious human being. It is my privilege to pass that message along.

2015 GLOBAL APPEAL, Meeting with Royalty and Visit to a Sanatorium

By José Ramirez, Jr.

On January 27, 2015, Yohei Sasakawa launched the 10th Global Appeal to end stigma and discrimination against people affected by leprosy. Mr. Sasakawa, Chair of the Nippon Foundation and UN Goodwill Ambassador on Leprosy invited speakers from all over the world, including a video message from Ban Ki-moon UN Secretary-General, and His Holiness the 14th Dalai Lama of Tibet.

The main speaker at the launching was Prime Minister Shinzō Abe of Japan. Mr. Abe was accompanied by First Lady Akie Abe. Mr. Abe emphasized the importance of eliminating laws and practices that discriminate against persons affected by leprosy. Following his presentation, the Global Appeal, signed by nursing organizations throughout the world, was read by Mr. & Mrs. Abe and representatives from Japan, India, Ethiopia, Brazil, Philippines, and the United States. I was honored to represent the U.S.

This unique event was also attended by persons affected by leprosy from 11 different countries, and were presenters at the International Symposium on Leprosy: “Why Leprosy Now?" This symposium was held following the launching of the global appeal.

The next day, nine guests, including Magdalena and I, representing six countries (Japan-Mr. Hirasawa and Mr.

Emperor Akihito greeting Mr. Narsappa and Mr. Venegopal from India, with Mr. Sasakawa behind the Emperor. Magdalena Santos Ramirez and José Ramirez, Jr. wait for their formal introduction. In the foreground is Empress Michiko greeting other persons affected by leprosy.

Photo is by Imperial Palace Photographer

Mori; USA, India- Mr. Narsappa and Mr. Venegopal; Philippines-Ms. Ibardaroza; Ethiopia- Mr. Misstru and Indonesia-Mr. Manek) were driven to a very special place in Tokyo. The place was the Imperial Grounds, specifically the private residence of Emperor Akihito and Empress Michiko. These two gracious giants of diplomacy, compassion and royalty received us with affection and kindness, never hesitating to welcome us to their simple residence. The Emperor asked me about my treatment at Carville and about my role as an advocate. The Empress asked both Magdalena and I about our respective mothers and hometown of Laredo, along with our current home in Houston and expressed a desire to visit the U.S. again. She also congratulated us on our efforts to share the truth about how injustices have occurred towards persons affected by leprosy. The Emperor had his interpreter and the Empress spoke perfect English. Neither appeared rushed, greeting each of us individually. A 10 minute audience became a 50 minute visit with royalty.

After our unforgettable visit we were met by many members of the media, asking all sorts of questions. One of the most memorable responses was from Mr. Narsappa of India. He shared telling Empress Michiko that his own family was unwilling to touch him, but she held his hand for many minutes. Regrettably, those of us affected by leprosy have many labels, including “untouchables.” On this visit to Japan, in a simple room with many windows and a panoramic view of the Royal Garden, Emperor Akihito and Empress Michiko dispelled this myth, even though it was only for a moment. I recalled the simplicity of their private residence and how the sweet and soft smell of the Empress’s perfume on her hands gently transferred over to our hands. It was a scent of royalty.

After such an exciting two days the group wondered what else could possibly top those experiences with Mr. Sasakawa, the Prime Minister and Royalty. Our own question was answered the next day as we visited our brothers and sisters at two sanataria.

The first visit was to the National Suruga Sanitarium. The director, Dr. Kazuo Fukushima and the assistant director, Dr. Rie Roselyne Yotsu explained that the facility used to accommodate up to 400 residents and now was used primarily to render palliative care for elderly and blind residents. The view of Mt. Fuji from the highest point of the sanitarium was magnificent. However, as many of us who have been institutionalized due to a diagnosis of leprosy, being in isolated locations and denied basic human rights, the beauty of such a place was likely not routinely appreciated by the residents.

Another visit was to the oldest privately operated sanitarium run by a religious organization. A surprising meeting was with Tokyo Fujiwara who excitedly described how he learned in the 1950’s that leprosy was curable after reading Betty Martin’s Miracle at Carville. His excitement elevated even more after I shared with him that Mrs. Martin and I worked together on advocacy. Connecting with brothers and sisters affected by leprosy continues to be a loving experience for me.

DO NOT ASK FOR WHOM THE BELLS TOLLS, ITS TOLL FOR THEE -Ernest Hemingway

By Father Charles Landry

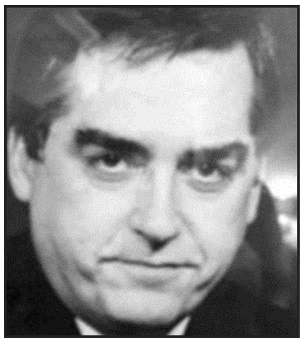
The bells of Sacred Heart Chapel have been restored and are in place on the roof connected to the chapel on the South Side. They are gorgeous. We offer a special thanks to Aimee Burrus, Segerant Major Charles Clay and the employees of Gillis W. Long Installation. Some time ago Aimee Burruss planted a seed into my mind as well as in the minds of the staff of Gillis W. Long personnel to perceive what could be done to restore the beautiful bells of Sacred Heart Chapel on the Carville facility. From that seed, growth began to spring forth and the fruition of that growth culminated in the placement of the bells in the belfry and subsequent blessing on **Sunday, October 20, 2013** immediately following the 8:30 a.m. Eucharist.

We surely thank Aimee and Stuart, Connor and Caleb, who supported her. Also, thanks to John and Marie Marchand, COL John Angelloz, and Sergeant Major Charles Clay, Frank Panepinto, Henry Glass, and the many workers who made this restoration possible.

With the Lord's guidance and our using the gifts and talents of the Lord, **Together We Can!**

Dr. Robert C. Hastings (1938-2014)

By Dr. David Scollard



Dr. Robert C. Hastings, physician, pharmacologist and internationally distinguished leprologist, passed away on 15th December, 2014, at the age of 76, after a long illness. Affectionately known to colleagues around the world as 'Bob', he earned his medical degree *summa cum laude* at the University of Tennessee, and a PhD in Pharmacology from Tulane University. He was a Commissioned Officer in the United States Public Health Service, and spent his entire career at the USPHS Hospital at Carville, Louisiana. In addition to his clinical duties there, he was a leading investigator in studies of the pharmacology of several important drugs used in leprosy. Over a remarkable 40-year career, from 1968 to 1998, he was an author or co-author on nearly 80 peer-reviewed publications dealing with anti-mycobacterial and anti-inflammatory drugs in this disease and Editor of *The International Journal of Leprosy* from 1979-2002.This included seminal work on the treatment of leprosy reactions with thalidomide. He retired as Chief of the Laboratory Research Branch of the US National Hansen's Disease Programs in 1994.

Editor's Note

Dr. Hastings was the first physician I met in 1968 when admitted to "Carville". He did his magic in relieving me of physical pain and eventually introduced me to Thalidomide. Thalidomide helped me to defuse the 17 reactions I experienced while at Carville. I will be forever grateful to Dr. Hastings for his passion to help us heal.

The New Generation

By José Ramirez, Jr.

The children of my wife, Magdalena, and I, were born in Houston, Texas. The first child, José Roberto (J.R.) now 36 and the second, Erika Betzabe, now 30, had an extraordinary childhood. Not because they were children of two social workers, or that they have over 39 cousins, nor because they spent several nights at the national leprosarium in Carville, Louisiana when their father returned for a checkup. It was because they grew up in a place, Houston, now considered the most ethnically diverse community in the United States, surpassing New York City.

The exposure to such a diverse group of friends and colleagues has allowed our children to be receptive to differences in cultures, languages and religions. It has added to the quality of their sensitivity in respect to the effects of stigma.

A spirited group of young adults as embracing of diversity as our adult children, were our colleagues during a retreat in Gotemba, Japan at the base of Mt. Fuji during February, 2015. The retreat, hosted by the Nippon Foundation of Japan, was comprised of persons affected, or impacted, by leprosy from different countries.

The purpose of the retreat was to discuss two significant issues which touch all who have experienced the effects of the leprosy bacilli entering their bodies. These issues included: identifying partners/stakeholders in carrying out the legacies of the first generation; and strengthening the participation of persons affected by leprosy in leprosy services.

Besides the active involvement of the participants, and their ease interacting with attendees representing different cultures, this new generation of young people is already doing something to change perceptions, and create positive images. Their stories ………. their work……… their contributions, are worthy of a novel.

Kristie Lane Ibardaloza, age 26, was born and raised on Culion Island, Philippines. Culion, as the community is known, was once a word not to be mentioned in the Philippines as it generated fear. Culion is where persons with leprosy were sent for life. Kristie's grandfather was sent there due to the disease and she inherited a culture of people unwilling to be defined by an illness. Kristie applied for and received a scholarship from the Sásakawa Memorial Health Foundation. She attended the Philippines Women's University and is now a nurse at the Culion Hospital. She is very proud of her heritage and even prouder to be giving back to her community. She represented the Coalition of Leprosy Advocates of the Philip-

NEW GENERATION: L-R, Hang Yibing, Testaye Tadesse Haile, V. Meena Rani-Vagavethali, Thiago Pereira de Silva Flores, and Kristie Lane Ibaradaloza.
Photo by José Ramirez, Jr.

pines (CLAP).

Another retreat attendee was V. Meena Rani-Vagavethali, 23 years old from India. She was born and raised in a leprosy colony though she does not have the disease. Her father was abandoned by his family after his diagnosis at an early age; however, her father is not resentful and neither is Meena. Both realize that Meena's grandparents simply did not have the financial or medical resources to help their son. Meena describes her father as "an inspiration" and has dedicated her life, for now, to helping her father with electronic messaging and other support as he travels throughout India and globally as the President of the Association of People Affected by Leprosy (APAL). So until she decides to accept a marriage proposal (12 so far), she will continue to help her father serve as the best advocate in his country. With her enthusiasm and beauty she could easily have been our second daughter.

A third member of the "new generation" is Thiago Pereira de Silva Flores, age 29, from Brazil and a member of MORHAN (an advocacy organization in Brazil). Thiago is one of the hundreds of "Filhos Separados" or Children Separated. Brazil had the practice of separating children immediately after birth from parents who were diagnosed with leprosy. As a result, Thiago was adopted but due to destroyed records he will never know who his birth parents were. However, he is motivated by their history and thus now is a strong advocate for restoring rights, dignity and respect for those affected by leprosy. He is an attorney and an accomplished cook.

A fourth attendee was Hang Yibing, 24 from China representing Joy In Action (JIA). Ms. Yibing is one of many college students throughout China who have taken on the battle cry to change perceptions and improve the quality of life for many persons affected by leprosy still living in leprosariums. These facilities have fallen into disrepair and students volunteer to participate in a work camp project. This project includes making a commitment to spend two weeks at the leprosarium repairing buildings. Twenty-nine universities in nine districts, with 20 volunteer students at each of the sites, have participated during their summer and winter vacations. Between 2001-2013, JIA organized 619 volunteer work camps with 13,340 volunteers in 61 leprosy villages carrying out 1,750 projects. The outcome of this exemplary volunteerism is that both students and residents of the leprosarium have learned to interact with others of different generations, and have enhanced their ability to cooperate with newly found strangers, now accepting each other as "family."

Another member of the "new generation" is Testaye Tadesse Haile. He is older, age 53, than the others. He is married, has four children and with 10 years' experience working as a teacher. He was inspired by the parents of the children he taught. Their parents were affected by leprosy and experience much stigma. Mr. Haile became friends with parents and chose to change perceptions via education, compassion and understanding. His purpose at the retreat was to learn more about advocacy and strategies to reverse discrimination directed at persons affected by leprosy. He represented the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL).

These individuals are indeed part of the new generation. Their commitment to helping others should result in outcomes that will allow persons affected by leprosy to live with dignity and respect. The Nippon Foundation did an outstanding job in in locating such dynamic individuals. Persons affected by leprosy throughout the world salute their efforts.

Local Students Learn Valuable Lesson about Social Justice

By Aimee Buress

St. Theresa Middle School in Gonzales, LA had a special assignment this school year. Mrs. Kim Lacinak, St. Theresa's Director of Religious Education and Fr. Eric Gyan, pastor at St. Theresa of Avila Catholic Church, decided that each grade level at St. Theresa needed to complete a "service project." Fr. Charlie Landry, pastor at St Gabriel Catholic Church and Sacred Heart Chapel in Carville, is the grade level Chaplain for the sixth graders at St. Theresa. Mrs. Lacinak and Fr. Charlie decided the sixth graders would benefit from visiting The National Hansen's Disease Museum and the Sacred Heart Chapel at the Gillis W. Long Center to learn more about social justice and the Corporal Works of Mercy.

St. Theresa Middle loaded 73 excited sixth grade students on a bus and headed to the museum and chapel. On the way, their travels took them down the river road to a bend in the Mississippi River to the old Indian Camp Plantation. Once through the gates, their first stop was at the chapel where Fr. Landry said mass with the students. After mass, the students were divided into two groups. One group toured the museum under the direction of Mrs. Elizabeth Schexnyder. As stated on the U.S. Department of Health and Human Services webpage, "The National Hansen's Disease Museum promotes understanding, identification and treatment of Hansen's disease and expands students understanding of how people with physical disabilities live". At the museum is where the "real" learning of social justice began. The students first watched a short film explaining the journey of the Hansen's disease patients . Next, the students were able to explore the museum with the audible tour guides. The students saw how people in 1894 were brought in handcuffs and lived behind a barbed wire fence. They were able to understand the injustices, discrimination and hardships the innocent patients suffered. Here they were able learn and understand about the changes in social attitude toward Hansen's disease as it moved from a "curse" with mandatory quarantine to a bacterial infection that is now curable with outpatient treatment. They also realized how the Daughters of Charity worked tirelessly at the facility which is a great example of how we as Christians are called to live. The sisters gave their life to the treatment of the patients. Sisters and Fr. Landry wanted the students to understand the philosophy of "what you do to the sick and needy, is what you do to Christ". Sisters and Fr. Landry also stressed that we all need to show mercy towards others.

As one group toured the museum, the other group listened to Captain Jackie Manton, National Guard YCP Director, about the Youth Challenge Program. The YCP program deals with many at-risk adolescents who are given a chance to change their future. The sixth graders then had the pleasure of listening to Mr. Frank Panepinto explain the history of the Gillis Long Hospital. He shared personal stories about meeting the patients and interacting with them on a daily basis. He explained to the students how he remembers feeling so bad for the patients when they were not allowed to live freely as we do today. The students were very moved with his heart felt stories of the days of "social injustice".

The lessons that day were invaluable. In one short visit, the students were able to gain knowledge of the Corporal Works of Mercy, tolerance, multicultural education and Louisiana history. What a great lesson on social justice!

First Advocates: The Daughters of Charity and the Louisiana Leper Home

By Reagan Laiche

The Louisiana Leper Home, the National Leprosarium or simply Carville. This isolated place surrounded by the Mississippi River seventy miles northwest of New Orleans, became home to those outcast from society with a diagnosis of leprosy in 1894.

While much has been written regarding the stigma, isolation, the patients' reform movement and the eventual 'miracle' of the 1940's drug therapy success, less attention has been paid to patient advocacy by the Daughters of Charity who arrived in 1896. Through letters written to their Sister Superior, the Louisiana Board of Control and the Archbishop of New Orleans, the Sisters expressed feelings of joy, sadness, isolation and frustration. Were it not for the steadfast dedication of the Sisters, the patients' reform movement and the 'miracle' may not have happened.

As their tenure turned from years to decades, the Daughters of Charity advanced the physical condition of the

Father Colton and the First Sisters. Sr. Sister Beatrice Hart, Chief Nurse and Sister Servant, Sr. Cyril Coupe (nurse), Sr. Annie Costello (nurse) and Sr. Mary Thomas Stokum (nurse)

Home from run-down slave cabins to full-fledged research hospital.

Letters detailing the routine and often mundane daily chores help to establish how integral the Sisters were as patient advocates. They advocated not just for basic needs but for the medical treatment only a research hospital could provide.

What may be considered simple now, the Sisters saw to it that the patients had a suitable place for dining. Sr. Beatrice wrote to Emmitsburg: “They looked comfortable compared with the dirty tables in the cabins.” The Sisters also brought a sense of dignity in death. As Sr. Beatrice wrote “… they were thrown like dogs into the grave the same day they died. I have insisted on a Christian burial…”

For decades, the Sisters provided a voice for the patients to the outside world. They created space for the patients to plant gardens, direct in-house plays as well as eventually to find their own voices through the patient newsletter developed in the 1930’s.

Understanding the story of leprosy includes understanding the work done by the Daughters of Charity during their mission. The mission officially ended in 2005 but the dedicated service of the Daughters of Charity to sufferers of leprosy provides a different narrative which extends beyond the years of the Home. It built the foundation from which the patients’ rights movement was able to flourish.

For more information regarding the advocacy of the Daughters of Charity at the Louisiana Leper Home, please see the author’s master’s thesis. Laiche, Reagan, "Labor in a Hopeless Land: The Daughters of Charity and Hansen's disease Patients at the Louisiana Leper Home, 1896-1926" (2014). *University of New Orleans Theses and Dissertations.* Paper 1928. http://scholarworks.uno.edu/td/1928

The author grew up along the Great River Road in St. James Parish, where knowledge of Carville inspired curiosity about those who lived and worked there. The author received a Master of Arts degree in History from the University of New Orleans in 2014.

A World without Disabilities

By José Ramirez, Jr.

The word "disability" is commonly associated with persons who are aging or who experience mobility by using a wheelchair. However, disability should also include those affected by cognitive, mental, sight, hearing or stigma challenges. Stigma, an act of labeling, rejection or unexplained fear, often experienced by persons affected by leprosy, was discussed at length at a global conference.

On February 25th -27th, 2015 the United Nations in Vienna, Austria, ESSL Foundation and the World Future Council hosted the "Zero Project Conference: Policies and Practices for Persons with Disabilities." With support from The Disabled People International (DPI). IDEA (International Organization of Persons Affected by Leprosy) and the Nippon Foundation Japan, I attended this meeting and made the conference's first-ever presentation on leprosy.

The conference, attended by over 500 individuals from 70 counties and multiple organizations representing governmental and non-governmental agencies, foundations and advocates focused on a world without barriers -- physical, emotional, technological and spiritual.

My presentation was titled "Disabled People International: Fighting Leprosy -- The Ignored Disability." It focused on knowledge, ignorance, blindness caused by leprosy, society blinded by myths linked to leprosy, self-advocacy, and self-care.

The saying that "knowledge is power" applies clearly to the scientific community when it relates to leprosy-curable, only mildly communicable, mode of transmission unknown, lengthy incubation period, and absence of disabilities when diagnosed and treated early. This type of knowledge about the disease is powerful and could help eliminate stigma and discrimination if simple facts as those mentioned are taught to all young minds and a concerted effort to integrate this into school health curricula.

However, ignorance about leprosy is even more powerful. Some of the incorrect "knowledge" spread throughout the world is that it is highly communicable, associated with sin, hereditary, deadly, not curable and persons affected by this disease are known simply as "lepers," or "patients." Regrettably, ignorance about leprosy is more common than the knowledge usually found in scientific journals.

One of the disabilities that can occur in those affected by leprosy is blindness, a condition known as lagophthalmos. This condition affects the eyelids whereby a person loses the ability to blink. By not being able to blink debris can enter the eyes, causing the dreaded "red eye" or severe infection and ending in loss of sight. Persons affected in such a manner often times are able to sharpen other senses in orders to maintain a semblance of their former lives.

Society is blinded as well as they become overwhelmed with myths and incorrect information about leprosy. If society were to be modeled as an eye, with four concentric circles representing (from outer to inner) System, Neighborhood, Family and Individual, the outcome would be **The Eye of Exclusion**. Six systems combine to create stigma: lack of political power; poor or inadequate housing in isolated locations or islands; inaccessible health services; poor economics via unemployment or underemployment; limited public education; and perpetuation of stereotypes by the media. These six systems give life to the "law of silence," or the practice of not challenging incorrect or difficult-to-believe myths, e.g., leprosy causes fingers to fall off.

The Eye of Exclusion is slowly being surpassed by **The Eye of Inclusion** via self-advocacy and self-care of persons affected by leprosy. By becoming our own spokespersons the "law of silence" can be overpowered by the "law of knowledge." A simple fact about leprosy can break the cycle of stigma, e.g., nerve damage to toes and fingers result in secondary infections and thus amputations. During this presentation, knowledge did overpower ignorance.

Many of those who attended the presentation on leprosy expressed dismay to find out that the disease continues to survive during modern times. The attendees stated that they associate the illness with biblical or ancient times. I emphasized that even through WHO (World Health Organization) typically reports only new cases per year (less than 300,000), these are approximately 15 million affected (under treatment or cured of the bacilli) and 150 million impacted (extended family members) by leprosy who daily experience the effects of stigma and loss of basic human rights.

Entertainment at the conference was very inclusive as Franz Joseph Huainigg, the first person with a disability elected to the Austrian Parliament and accessing public buildings in a wheelchair, welcomed everyone to the reception. Among many unique forms of entertainment was the Waltz performed by high-level-class wheelchair dance couple Brigitte Kröll and Werner Kaiser. Their performance was inspiring and worthy of being special guests on the TV show "Dancing with the Stars."

Besides the inspiration from the talented dancers, the potential for world-wide collaboration for having a "world without disabilities," and their siblings stigma and discrimination, was also extremely inspirational.

United Nations in Vienna

Left to Right, Javed Abidi, Chairperson of Disabled People's International (DPI), Magdalena Santos Ramirez and José Ramirez, Jr.

Photo by Erika Betzabe Ramirez

VOICES OF PEOPLE AFFECTED BY LEPROSY

By José Ramirez, Jr.

In 2007, the United Nations Convention on the Rights of Persons with Disabilities was introduced and adopted by the United Nations body, with 143 countries ratifying the convention. This document basically mandates equality in all domains of society, including but not limited to accessibility; right to life on an equal basis with others; protection from cruel and degrading treatment; etc.

Once the convention was adopted, the Conference of States Parties commenced annual meetings. The 8th conference will be held at the United Nations in New York City June 9th-12th. These conferences regrettably have not been inclusive of presentations on Hansen's disease. For the 2015 conference, the Disabled People's International (DPI), in collaboration with The Nippon Foundation of Japan and Mr. Sasakawa, Goodwill Ambassador for the Elimination of Leprosy, have planned for the first ever side event on leprosy. DPI is a global network of national organizations of people with disabilities which has a presence in more than 150 countries, and has recently undertaken an initiative to include persons affected by leprosy in the disability movement with the hope of generating a greater awareness of and visibility for leprosy-related issues amongst the national and international disability movements.

The "side event" is titled "Voices of People Affected by Leprosy" and will occur on June 10th at the United Nations. Included in the presentation will be comments from The Nippon Foundation, Mr. Sasakawa as Goodwill Ambassador, The Permanent Mission of Ethiopia, P.K. Gopal from India, José Ramirez, Jr. from the USA and Mr. Joseph Abidi. All who have registered for the 8th conference have been invited to this event and hopes are that others with disabilities not related to leprosy will be able to learn about injustices directed at those affected by leprosy and thus become advocates for the elimination of discrimination and stigma.

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email: ksaffier@yahoo.com
PH: (925) 370-5200 Ext.:4743
Public Health Nurse – Barbara Hobson, RN
PH: (925) 313-6757
email: Barbara.Hobson@hsd.cccounty.us
Community Health Worker - Sebastian Basalic
email: Sebastian.Basalic@hsd.cccounty.us

MIAMI HD CLINIC
Jackson Memorial Hospital
1611 N.W. 12th Avenue
ACC East – 2nd Floor
Department of Dermatology
Miami, FL 33136-1096
PH: (305) 585-7348 Fax: (305) 585-6397
Primary Physician - Dr. Anne Burdick
email: Aburdick@med.miami.edu
Public Health Nurse - Gail Chepenik, RN
email: gchepenik@jhsmiami.org

NEW YORK HD CLINIC
Bellevue Hospital Center
Department of Dermatology
462 First Avenue, Room 17-N-7
New York, NY 10016
PH: (212) 562-5670 Fax: (212) 263-6423
Primary Physician - Dr. William Levis
email: william_levis@yahoo.com
Public Health Nurse - Tina Rendini, RN
PH: (212) 562-6096
email: tinarendini43@gmail.com
Physical Therapist - Louis Iannuzzi, P.T., C.Ped.
email: Lni1@nyu.edu

PHOENIX HD CLINIC
Maricopa County Health Department
1645 East Roosevelt Street
Phoenix, Arizona 85006
PH: (602) 372-2039 Fax: (602) 372-3862
Primary Physician - Dr. Ronald Pust
Tucson Office: (520) 626-5650
Cell: (520) 668-6441
email: rpust@email.arizona.edu
Public Health Nurse - Brenda Cabrales, RN
PH: (602) 372-1407
email: brendacabrales@mail.maricopa.gov
Physical Therapist - Tracy Carroll, MPH
email: tcarroll@email.arizona.edu PH: (520) 312-5750

SAN DIEGO HD CLINIC
HHSA, North Central Regional Center
5055 Ruffin Road, Mail Stop: N-513
San Diego, CA 92123
PH: (858) 573-7338 Fax: (858) 573-7325
Primary Physician - Dr. Erik O. Gilbertson
email: erik.gilbertson@sdcounty.ca.gov
Public Health Nurse – Krisanto Equipado, RN
email: krisanto.equipado@sdcounty.ca.gov (858) 573-7320

SAN JUAN HD CLINIC
University of Puerto Rico
Medical Sciences Campus
School of Medicine - Dept. of Dermatology
P. O. Box 365067
San Juan, PR 00936-5067
PH: (787) 765-7950 Fax: (787) 767-0467
Primary Physician - Dr. Pablo Almodovar
email: dermatol.rcm@upr.edu
Public Health Nurse - Sonia Santos-Exposito, RN, BSN
PH: (787) 758-2525, Ext. 5503
email: sonia.santos@upr.edu

SEATTLE HD CLINIC
Harborview Medical Center
2 West Clinic – 359930, 325 Ninth Avenue
Seattle, WA 98104
PH: (206) 520-5000 or (206) 744-5113
Toll Free: (877) 520-5000
Fax: (206) 744-5109
Primary Physician - Dr. James Harnisch
email: jpharnisch@comcast.net
Public Health Nurse – Chinh Tran, RN
email: tranc@u.washington.edu

SPRINGDALE HD CLINIC
Joseph H. Bates Outreach Clinic of Washington County
614 E. Emma Avenue, Suite 247
Springdale, AR 72764
PH: (479)-751-3630 Fax: (479) 751-4838
Medical Director: Naveen Patil, MD, MHSA, MA
PH: (501) 661-2415 (Office) (501) 772-4809 (Office Cell)
Fax: (501) 661-2226
email: naveen.patil@arkansas.gov
Primary Physician: Linda McGhee, MD
PH: (479)-521-0263 PH: (479) 973-8450 (office)
email: *lmcghee@uams.edu*
Public Health Nurse - Sandy Hainline Williams, RN
PH: (479)-751-3630 Cell: (479)-422-0190
email: *sandra.hainline@arkansas.gov*

TEXAS HD CLINICS

Dallas County Health & Human Services
2377 N. Stemmons Freeway, Suite 522
Dallas, TX 75207-2710
PH: (214) 819-2010 Fax: (214) 819-6095
Physicians - Dr. Jack Cohen/Dr. Sharon Nations
email: jbcohendo@aol.com
PH: (817) 753-6633 (private practice)
email: sharon.nations@utsouthwestern.edu
PH: (214) 819-2010
Public Health Nurse - Claire Keels, RN
email: Claire.keels@dallascounty.org

Houston Department of Health and Human Services
Northside Health Center
8504 Schuller Street
Houston, TX 77093
PH: (832) 393-4804 Fax: (832) 393-5247
Physician - Dr. Terry Williams/Dr. Steven Mays
email: Tmwill3502@aol.com
PH: (281) 332-8571
email: Steven.Mays@uth.tmc.edu
PH: (713) 500-8329
Public Health Nurse – Barbara Matinez
email: Barbarah.Martinez@houstontx.gov
Main: (832) 393-4771 Cell: (713) 582-2517
Fax: (832) 393-5245

Texas Center for Infectious Disease
2303 S. E. Military Drive
San Antonio, TX 78223
PH: (210) 531-4526 Fax: (210) 531-4508
Physician - Dr. Adriana Vasquez
PH: (210) 531-4565
email: adriana.vasquez@dshs.state.tx.us
Physician - Dr. Lynn Horvath
PH: (210) 531-4524
email: lynn.horvath@dshs.state.tx.us
Physician - Quatulain F. "Annie" Kizilbash, MD, MPH
PH: (210) 531-4959
email: quratulain.kizilbash@dshs.state.tx.us
Public Health Nurse - Debbie Mata, RN
PH: (210) 531-4576 PH:(210) 531-4295
Cell: (210) 834-9002
Appointment Secretary (210) 531-4526
email: debbie.mata@dshs.state.tx.us

Department of State Hlth Services Region (HSR) 11
601 W. Sesame Drive
Harlingen, TX 78550
PH: (956) 423-0130 Fax: (956) 444-3295
Physician - Dr. Richard Wing
email: richard.wing@dshs.state.tx.us
Public Health Nurse – Melissa Davis, RN
PH: (956) 423-0130, Ext. 5574
email: Melissa.davis@dshs.state.tx.us

Other Clinics

HAWAII HD PROGRAM
Hawaii State Department of Health
Hansen's Disease Community Program
3650 Maunalei Avenue
Honolulu, HI 96816
PH: (808) 733-9831 Fax: (808) 733-9836
Program Manager: Lori Ching, RN
Direct Line/Voice Mail: (808) 733-4663
email: lori.ching@doh.hawaii.gov
Office Physical Address:
Diamond Head Health Center
3627 Kilauea Avenue Room 102
Honolulu, HI 96816

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The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

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

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

FACTS ABOUT HANSEN'S DISEASE

What is HD?

Hansen's disease, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr. Gerhard 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 difficulty and counteract most of the fears generated by the folklore surrounding this disease.

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

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

Where is HD Found?

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

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began who are still living. This includes approximately 3,300 cases currently receiving medical treatment for HD by the NHDP Ambulatory Care Program Clinics or private physicians with assistance from the NHDP. There were 150 new cases reported to the registry in 2008. California, Hawaii, Louisiana, Florida, Massachusetts, and New York contributed the largest number of cases in 2008.

How Does HD Spread?

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

How is HD Treated?

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

NHDP SERVICES Website: www.hrsa.gov/hansens