

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JULY - DECEMBER
2008**

**VOLUME 64 - 6
\$2.00 PER YEAR**



José Ramirez, Jr. is awarded the National Americanism Award at the Forty and Eight Promenade Nationale: Pictured left to right are Chef de Chemin de Fer 2008 Bernie Sampson, Americanism Directeur Lloyd Koeller, and recipient José Ramirez, Jr.

(Story on page 3)

CONTENTS

July—December 2008 Vol. 64-6

Americanism Award Winner José Ramirez, Jr. <i>Mike Wood</i>	3
Rediscovery and Apologies <i>José Ramirez, Jr.</i>	4
Pity as a Form of Injustice <i>Lian Law</i>	4
The Ambulatory Care Program <i>Irma E Guerra</i>	5
American Leprosy Missions <i>Ymelda Beauchamp</i>	7
NHDP Provision of Mycobacterium Leprae <i>James L. Krahenbuhl, Ph.D.</i>	8
WHO meeting in New Delhi, India	9
Hansen's Disease in Taiwan <i>Ten-Pei Lee</i>	10
Leprosy and Human Rights <i>Douglas Soutar</i>	11
An Apology long Overdue <i>Valerie Monson</i>	12
Commitment to Influence Change <i>Doe Sung Lim</i>	13
Grassroots work in Ghana <i>Kofi Nyarko</i>	14
Hansen's Disease Clinics.....	15

*All correspondence concerning **The STAR** should be addressed to:*

**Voiture Nationale
777 North Meridian St Suite 204
Indianapolis, IN 46204-1065**

EDITORIAL BOARD

Abel Aparicio -**Editor**
José Ramirez, Jr -**Managing Editor**

CONTRIBUTORS:

Mike Wood
Elizabeth Schexnyder
Irma Guerra
Ymelda Beauchamp
James Krahenbuhl, Ph.D.
Bernie Sampson

Stanley Stein

Founder - Editor, 1941 - 1967

The contents of this publication may be reproduced in whole or in part with credit given to **The Star**, Carville, Louisiana.

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

After you have read **The Star**, please pass it on to a friend and if **The Star** reaches you at a library, please place it conveniently for readers.

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.

MOVING SOON?

Please let us know six weeks before you move what your new address will be. Include your old as well as your new address. □

**\$2.00 Per Year Domestic
\$5.00 Per Year Foreign**

National Hansen's Disease Program
1770 Physician Park Dr.
Baton Rouge, LA 70816
Phone: (800) 642-2477
Fax (225) 756-3806
Website: www.hrsa.gov/hansens

JOSE' RAMIREZ, JR. IS AWARDED THE FORTY AND EIGHT NATIONAL AMERICANISM AWARD by Mike Wood

On September 6, 2008 Jose' Ramirez, Jr., the Managing Editor of The Star was awarded the Forty and Eight Americanism Award at their Promenade Nationale in Orlando, FL by Chef de Chemin de Fer Bernie Sampson assisted by Nationale Americanism Directeur Lloyd Koeller. This award is presented annually to a candidate that exemplifies the American way of life and principles. His wife, Magdalena, two adult children and two of twelve siblings, Idalia Skates from Houston, and Yolanda Garcia of Laredo, TX attended the black-tie event in Florida.

The Forty and Eight is an Honor Society of American veterans created in 1920, and The Star's primary funding organization. It draws its origin from World War I. Millions of American troops in France were transported to the front lines 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 (Chapters) began organizing as outstanding veterans were invited into their membership. Membership is still by invitation only. Dedicated to the needs of their fellowman, the Forty and Eight raises funds and supports not only The Star and the Carville Museum, but funds a national nursing scholarship program, various child welfare programs, provides aid to veterans and continues to promote Americanism at both the local and national levels. The American Legion first came to Carville at the request of the patient-veterans in 1931, and The Forty and Eight became involved immediately, raising the funds for The Star's first printing press in 1943 under the Carville Star program, the organizations second oldest program.

Jose' is a past resident at Carville and was diagnosed with Hansen's Disease (HD) in 1968. He has worked tirelessly in supplying knowledge and sharing his experiences about Carville and HD. Jose' gained his BA degree at Louisiana State University in 1971 and went on to earn a Masters Degree in Social Work in 1974. He is now employed in that field in Houston, Texas by the Mental Health and Mental Retardation Authority (MHMRA) of Harris County. Jose' was awarded the Houston "Disability Advocate of the Year Award" presented by Mayor Bill White in 2004.

Jose' has spoken about HD to many professional groups educating them about Hansen's Disease all over the world. He has had over 30 articles published, and has appeared in the PBS nationally televised program "Triumph at Carville". Jose' will have his book; Squint: My Journey with Leprosy released in February 2009. He will host a book signing at the HD Museum in Carville, LA.

Jose' is a member of many professional organizations and has earned numerous awards, among them are: "Fighting Spirit Award" presented at the United Nations by Japan's Nippon Foundation, the "Etem Utku Medal" by the Istanbul Medical School in Turkey, and Houston Social Worker of the Year. He was invited by the World Health Organization's Special Ambassador on the Elimination of Leprosy to address the United Nations' International Commission on Human Rights in Geneva Switzerland and was invited by the Friends of Fontilles, an international anti-leprosy organization, to address the national press corps of Spain in Madrid in conjunction with World Leprosy Day.

Jose' is married to the love of his life, and they have two outstanding children, Erika and Jose' Roberto (J.R.) The Ramirez family makes their home in Houston, TX. As the Directeur of the Forty and Eight Carville Star program, I am so proud to see Jose' be awarded our National Americanism Award, and I feel very fortunate to call him my friend and associate.

Squint: My Journey with Leprosy:

When the health department doctor gave José Ramirez, Jr. the *Handbook for Persons with Leprosy*, he learned his fate. The diagnosis meant exile and hospitalization in the only leprosarium in the continental United States---Carville, Louisiana, and separation from his parents, 12 siblings, girlfriend, and life-long friends from Laredo, Texas. In *Squint*, titled for the sliver of a window through which persons with leprosy in medieval times were allowed to view Mass but not participate, Ramirez tells a story of love and perseverance, becoming an international advocate on behalf of persons with disabilities.

FEBRUARY, 240 PAGES, 5 1/2 X 8 1/2 inches, 20 b&w illustrations, cloth, \$28.00T, 978-1-60473-119-4, call 1-800-737-7788 to order toll free.

REDISCOVERY AND APOLOGIES: An Editorial

By José Ramirez, Jr.

My employer, the Mental Health Mental Retardation Authority (MHMRA) in Houston, Texas honored me by acknowledging in the Agency's newsletter that I had received an award from a professional organization. The article mentioned my hospitalization at the Leprosarium in Carville, Louisiana.

Many of my co-workers approached me about the "new" knowledge they had gained about Hansen's disease (HD). This surprise came even though I had worked with them for decades.

The sharing of one's medical history is something that does not occur very often, even among the best of friends. However, the information about my HD always stirs the sleepy slumber of myths.

A unique thing happened after the newsletter was published. I received a phone call from a staff person in a department different from mine. The caller told me that her father had been a patient at Carville. She recalled how, as a little girl, she would visit her Dad at the hospital. His diagnosis was kept a well-guarded secret from her extended family. Her mother would emphasize that this illness had a long history of shame and stigma, and thus decided not to share the "secret" with the others. Even after death, his diagnosis remained a secret.

The article in the Agency newsletter resurrected these times of silence for my co-worker. She and her mother have chosen to reverse this silence and are now talking about returning to Carville. Their plan is to visit the National HD museum, as well as review his medical records in order to better understand his life at Carville.

On a much larger scale, others throughout the world are starting to find out about family members who lost their identity after being diagnosed with HD. Two of these places where silence is also being reversed are Kalaupapa Settlement in Hawaii and Lo-Sheng Sanatorium in Taiwan.

Both Kalaupapa and Lo-Sheng have received written apologies from their respective government officials – Kalaupapa from the Hawaiian State Legislature and the Lo-Sheng from the Taiwan Parliament. Breaking down the barriers of silence has opened up opportunities for the healing of emotional trauma experienced by almost everyone diagnosed with HD.

By allowing my employer to mention my medical history, I inadvertently touched the life of a colleague. The apologies that have occurred in Hawaii, Taiwan and Japan have also touched the lives of persons affected by HD and their families. Hopefully, the new President of the United States Barack Obama will follow the footsteps of others and extend an apology to the thousands who experienced emotional pain and suffering because of their involuntary admission to Carville.

Pity as a Form of Injustice

Lian Law, IDEA, Student, University of Rochester

Many people consider travelling to another country a once in a life time experience. However, because of my parents, Anwei and Henry Law, and their association with IDEA, I have been fortunate enough to travel to many different places. When I tell most people this, they assume it is merely for family vacations. However, when I travel, I do not go into a country as a tourist for entertainment. I go to learn and to experience.

Travelling to any country is an eye-opening experience. Each time, I am exposed to something different. Every country has its own unique diversity, not merely a diversity of ethnicity but a diversity of thinking, perspective and experience. However, one thing that remains a constant no matter where I have travelled is the integrity and hospitality of individuals.

While travelling, I have witnessed the injustices of the law, poverty, and the violation of human rights, but perhaps one of the greatest injustices that one can inflict on another person is that of pity. I have come to learn that nothing undermines one's inherent dignity more than to pity another person.

When one pities someone, one focuses solely on their inability rather than their ability. To pity a person is to imply that they are inferior and comparably "underprivileged." It is an easy way to focus on someone's state of being rather than their character and is often based on faulty assumptions. It is a form of degradation to pity someone because it is to say that you are superior. Perhaps the worst thing about pity is that it is often the flaw of good-hearted people with good intentions who are unaware of the consequences of their actions.

The people I have met when I travelled have often been subject to various injustices, including pity, but nothing is more resounding than their generosity and true depth of character. It is the people I meet that makes travelling have such a profound impact. Travelling has always been an opportunity to become more involved in the global community. One becomes a citizen of the world by traversing the boundaries of one's own country and forging ties between individuals.

The Ambulatory Care Program
Irma E. Guerra
National Hansen's Disease Programs, Baton Rouge, LA

History

The United States Public Health Service Hospitals, originally established as Marine Hospitals for merchant seamen under President John Adams in 1798, were located primarily in the coastal areas of the U.S., and had been providing Hansen's disease (HD) services for many years. Except for the USPHS hospital in Carville, LA known at that time as Marine Hospital #66), the nation's PHS hospitals were closed by the Federal Government on October, 1981.

In an effort to provide continuity of care for HD in the U.S. and Puerto Rico, the Division of National Hansen's Disease Programs at Carville, under BPHC, HRSA, DHHS, developed the Ambulatory Care Program (ACP) in that same year. Through Contracts with healthcare facilities in areas where most of the patients live, the Outpatient HD Clinics were established in different types of settings such as University Medical Centers, State and County Health Departments.

Mission

The Mission of the Ambulatory Care Program is early diagnosis and treatment of HD in order to prevent deformity and disability. With this in mind, the ACP is aptly situated with its' network of HD Clinics throughout the country and Puerto Rico, to diagnose and treat, not only people in the surrounding communities, but within a large geographic area, including patients referred for diagnosis and treatment by physicians in adjacent states.

Outpatient Hansen's Disease Clinics

The professional staff at these Clinics has been providing HD care and treatment for many years, and have developed extensive expertise in this field. They serve as consultants to, and participate in, educational offerings for healthcare providers in their surrounding areas with regards to the early diagnosis and treatment of Hansen's disease. (See list of clinics on the back page of The STAR)

Patient care services offered at the Outpatient HD Clinics include:

- Medical and nursing assessments for HD
- Diagnostic procedures such as skin biopsy
- Recommended Baseline Laboratory studies
- Classification of disease and recommended treatment
- Medications for HD and required laboratory monitoring
- Follow-up clinical assessments during treatment
- Referrals to ENT, occupational and physical therapy, and orthotics as necessary for complications of the disease
- Patient and family education and informative materials

Patients who have complications from HD which can not be managed at the Outpatient HD Clinic, may be referred to the NHDP in Baton Rouge, LA. Professional staff at these Clinics can also consult with NHDP staff regarding clinical issues, and processing of biopsies,

Private Physician Program

As part of its' Mission, the ACP also has oversight of the Private Physician Program. This consists of physicians in private practice who provide HD care to persons who live too far from an Outpatient HD Clinic. The following services are available at no cost for private physicians:

- Consultation on treatment and management guidelines
- Medications for HD: dapson, rifampin, clofazimine
- Processing biopsies for histopathology and classification
- HD Surveillance Forms
- Audiovisual and printed educational materials for Professionals
- Patient education materials in English and Spanish
- Two-day comprehensive Hansen Disease Seminars for Physicians and other health care professionals

The NHDP is actively engaged in bringing an awareness to physicians across the U.S. that HD may be seen anywhere, especially among immigrants from endemic countries.

Our "awareness" message is:

1. Consider the diagnosis
2. Make a presumptive diagnosis
3. Send us a biopsy for confirmation and classification
4. NHDP will provide free Hansen's diseaseleprosy drugs and consultations with private physicians regarding management
5. If a case becomes complicated and unmanageable, we will accept patients at NHDP as referral cases.

The NHDP website www.hrsa.gov/hansens, is available for further information about HD, or the toll-free number, 1-800-642-2477, may be called 8-4:30pm, CST.

For a new or renewal **subscription** to The Star please fill out the subscription form below and mail your payment to :

Voiture Nationale
Attn: The Star Membership
777 North Meridian St., Rm. 204
Indianapolis, IN 46204-1065

Subscribe to The Star

Name: _____

Address: _____

Address2: _____

City/State/ZIP: _____

Country: _____

\$2.00 per year domestic \$5.00 Per Year Foreign

Make checks payable to: Voiture Nationale

My enclosed check is for ____ years and for ____ subscriptions for a total amount of \$_____

American Leprosy Missions By Ymelda Beauchamp

*In the epicenter of humanity, the American Leprosy Missions are true humanitarians
It is only with an understanding of their faith that the dedication of their work can be understood.*

All across the world American Leprosy Missions make a difference improving the lives of people, the communities, and the world they touch. I have known of the American Leprosy Missions existence since my early days at Carville, many years ago. Despite solid evidence of the Missions' work and charitable causes, they remained a myth in my life. Sometime last November a dear friend asked if I would be interested in becoming a member of the American Leprosy Missions Board. It was with much hesitation and prayer for guidance that I accepted. So it happened that in May of 2008 I headed to the hills of North Carolina for my first meeting as a new Board Member. I did much homework during my eight-hour commute from San Diego, still somewhat apprehensive of what I might encounter, and struggling to overcome an intimidation factor. It was nevertheless an exciting endeavor.

My surprise was one of wonder when I arrived at the meeting site, where I saw dear and familiar faces from my days at Carville. We embraced and we cried reminiscing about times gone by. The group of people I met was gracious, warm and hospitable. They could be anyone's co-workers and counterparts, and yet they do not fit into any standard organization. The American Leprosy Missions Board and Staff Members are non-pretentious. They were inviting and encouraging, witty and unassuming. Most importantly they welcomed me with smiles and open arms. In an instant their warm reception diffused all the fears I might have had.

During the meetings that followed I received a straightforward overview of the issues most related to providing treatment to people affected by leprosy. After two days of witnessing in absolute amazement their dedication for the work they do, their love for humanity and their faith, which leads them in their quest, I felt a healthy envy for them and their underlying commitment of "freeing the world of leprosy."

The ALM Board members create partnership with businesses, civic leaders, service organizations, everyday citizens and churches to promote contributions, which are used directly in establishing clinics in the remote areas of the world. Contributions are used for drug clinical trials, training programs, development of a leprosy vaccine, medical research for leprosy and other related diseases. Dollar per dollar, they work and give of their time and resources to improve the lives of many.

The indefinable spirit, which I witnessed in North Carolina in both, the board members and their wonderful staff, clearly follows the teachings of God. The members are led by their belief to better the lives of people affected by leprosy, to bring understanding of leprosy to the world, and to help eradicate stigma and prejudice. Every night while most of us remain comfortably in our homes, hundreds of people are diagnosed with leprosy around the world and often are confronted with ostracism and abandonment by their families. The American Leprosy Missions provide hope for those they can reach. They provide the funds and help to promote dignity to people who are often shunned by society.

When I left Asheville (location of retreat – ALM headquarters are in Greenville) I was overflowing with enthusiasm for ALM and all the Missions and their capacity to see challenges and barriers not as points of contention, but as compelling reasons to join forces and work together to bring a cure to a most misunderstood disease. So, in this spirit filled with faith, ALM inspires the world around them. But I am positive that no one has been as inspired as I. They are incredibly responsible, persevering and responsive to a great human need.

I don't know what my role is on the ALM Board, I am not a clinician, not a lawyer, not a doctor, or businessperson. My expertise is with children, with special needs. Whatever the future holds for me with this wonderful group of people, I feel that just by knowing the members of the ALM Board, I have already gained so much more than I can ever offer them. So for now anyway, and until my role is defined, I will follow the advice of someone very wise.... .."I will let the Lord guide me..."

NHDP Provision of *Mycobacterium leprae* to the World's Researchers

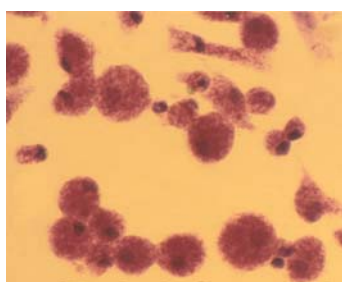
James L. Krahenbuhl, Ph.D.

Director, National Hansen's Disease Programs, Baton Rouge, LA

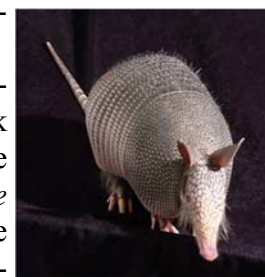
When Norwegian scientist Armauer Gerhard Hansen claimed he had discovered the causative agent of leprosy in 1873 he knew he was inviting controversy. He identified the rod shaped organisms as bacilli, a term coined by Louis Pasteur, the father of bacteriology, a few years earlier. Conversation was surely lively around the Hansen dinner table. By embracing the newly found germ theory for this disease, now known as Hansen's Disease (HD), Hansen was conflicting with the accepted hereditary theory championed by his future father-in-law, Cornelius Danielsson.

But in the intervening years since 1873 *M. leprae* and HD have been reluctant to give up their mysteries. We do not understand fully the route or source of transmission of HD. We do not understand who is susceptible to HD. There is no lab test to detect disease. Three to ten or more years may pass between infection and onset of symptoms, due likely to *M. leprae* being the slowest growing of bacterial pathogens (taking 13 days to divide compared to *E. coli*'s 20 minutes). *M. leprae*'s predilection for invasion of peripheral nerves is not understood. The immunological and genetic circuitry that underlie the complex broad clinical spectrum of clinical HD is fascinating but poorly understood. And, if Hansen were alive today he would be most shocked to learn that, 135 years after he identified *M. leprae* as the first bacterial agent of a human disease, the organism has yet to be cultured in the laboratory. This lack of large, routine quantities of pure *M. leprae* is the most formidable obstacle stymieing HD research.

M. leprae prefers the cooler parts of the body, the skin, ears and nasal mucosa. For about 75 years the only sources of *M. leprae* for research were nodules from patients' skin and ears. Obviously this was an unreliable, unethical source of poor quality bacilli. Two research milestones were promising. Limited growth of *M. leprae* was demonstrated in the cooler hind foot pads (FP) of mice in 1960 by Charles Shepard at the CDC. In 1970 Eleanor Storrs at Gulf South Research, New Iberia, LA and Waldemar Kirchheimer at Carville showed that the nine banded armadillo, with a core temperature 4 degrees below human body temperature, developed a systemic infection with *M. leprae* and billions of HD bacilli could be harvested from their internal organs after about 2 years. However, yields from FP of conventional mice proved too low for most experiments and, although armadillos could provide enormous numbers of *M. leprae* for certain experiments, they were too expensive to maintain as a routine source of HD bacilli.



Advances in cancer research produced genetically defective mice including so-called nude mice which lack the "T cells" so critical to a normal immune response (the gene for hair was coincidentally deleted). *M. leprae* will grow to 5 – 10 billion per FP in 4 – 6 months in the nude mouse. The FP become visibly enlarged and microscopic examination of the infected FP cells shows cells gorged with thousands of bacilli (stained red) just like they are in advanced lepromatous HD



in man.

Nude mice are costly (\$60 each) and expensive to maintain. Because they are severely immunocompromised and very susceptible to ordinary infections nudes must be housed in sterile cages on sterile bedding, provided with sterile air, food and water and cared for under aseptic techniques. But these costs pale in comparison to the costs of maintaining an infected armadillo, ~\$2,400 per year.

With funding provided by a grant from the American Leprosy Missions, Greenville, SC (www.leprosy.org) the NHDP harvests HD bacilli from a single infected nude mouse each Tuesday morning. Bacilli are purified, enumerated and dispensed first to NHDP researchers, who often congregate outside the laboratory like customers at a donut sale. The remaining bacilli are packed on ice and shipped overnight by FedEx to waiting researchers around the world. In the past 3 years 190 shipments have been made to the laboratories of 28 researchers in 9 countries, including the U.S. (New York, New Jersey, Baltimore, Miami, Denver, Duluth, Seattle), Canada, U.K., France, the Netherlands, India, Brazil, the Philippines and Australia.

The NHDP is now available to provide access to a routine supply of this valuable research reagent to researchers from multiple disciplines; immunology, molecular biology, cell biology, neurology, pharmacology, microbiology and epidemiology. Scientists can finally directly address basic HD questions about nerve involvement, host resistance mechanisms, early diagnosis, vaccination, and transmission. I think Armauer Hansen would be pleased to learn that we are finally making progress in unlocking the secrets of his disease.

REPORT OF THE INFORMAL CONSULTATION ON INNOVATIVE APPROACHES TO FURTHER REDUCE LEP- ROSY BURDEN IN COUNTRIES

World Health Organization, September, 2008

WHO convened a meeting in New Delhi, India with twelve participants representing various regions and expertise addressing challenges related to the future of leprosy control programs. Dr. S.K. Noordeen (President of Leprosy Elimination Alliance) and Dr. H.J.S. Kawuma (Medical Advisor for the German Leprosy Relief Association) co-chaired the meeting. The following are the “conclusions and recommendations” offered by the Consultative Group.

1. After an in-depth discussion on the merits and demerits of setting numerical targets and time frames, the Consultative Group recommended that the enhanced Strategy for reducing leprosy burden should include setting of realistic numerical targets based on grade 2 disabilities among the new cases which is likely to indirectly reflect the level of occurrence of new cases in the population. It was agreed to have a small working group on this issue to review available data and project targets for the future.

The Group firmly believes that setting a global target, based on reducing the occurrence of grade-2 disabilities among new cases in the population, is likely to have an impact on reducing the occurrence of new cases in the population.

2. In most of the previously high endemic countries current leprosy profile shows a relative low endemicity, while in others it is reaching the profile of rare disease status. The Group considered that under such a situation, risk of leprosy among the house-hold contacts is likely to achieve high significance.

The Group recommended that in areas where high proportion of new cases are being detected among contacts, examination of house-hold contacts at the time of diagnosis of a new case and providing single dose rifampicin to such house-hold contacts as prophylaxis would be a useful measure to reduce occurrence of leprosy in the community.

3. Recognizing the long duration and relatively complex studies needed for testing of efficacy and safety of newer drug regimens for anti-leprosy chemotherapy,

The Group recommended that it will be important to embark soon on testing of alternative treatment regimens. Such regimens will be particularly necessary to counter the possible threat of rifampicin resistance.

4. The Group stressed the importance of continuing research, particularly in key areas of disease prevention, drug development and operational research for improving tools and methods for disease control and improving the quality of clinical services, including referral services.
5. The Group recommended that capacity building of general health services personnel is important for providing adequate services for leprosy. However, capacity building programmes should carefully assess the needs and direct such efforts only to areas where leprosy occurs in order for the programme to be efficient and cost-effective.

6. The Group expressed concern over persistent weakness of supervision in many programmes which was seen even during the era of specialized national leprosy control programmes. The situation in the current integrated leprosy control era will need enhanced supervisory support, particularly at the field level.

The Group recommended that appropriate resources, particularly for mobility, should be made available to promote and strengthen effective supervision at all levels.

7. With decreasing occurrence of leprosy the issue of integration should be carefully re-assessed so that specialized services are available where necessary and at the appropriate level.
8. There is a need to focus on underserved populations so that the magnitude of leprosy among them is assessed and locally specific sustainable anti-leprosy strategies are developed with inter-sectoral collaboration.

People Affected by Hansen's disease (HD) in Taiwan

by Ten-Pei Lee, President, IDEA Taiwan

The road to dignity for the people affected by Hansen's disease in Taiwan has been long and painful. We, as residents of the Lo-Sheng Sanatorium, have united to restore our lives.

Lo-Sheng Sanatorium was established in 1930 under the Japanese colonial rule. This action reflected the extreme isolation policies of the Japanese government during this era. After WWII, Lo-Sheng Sanatorium continued under the new government. Because of these policies on segregation, persons with HD in Taiwan have been deprived of freedom, dignity, health rights, families, homeland, and formal education. Our human rights were also violated, including forcible labor, prohibition of marriage, sterilization, abortion, forced to endure clinical experiments, and medical ethical violations. In spite of these horrible violations, residents and their children have lived in the sanatorium for many years and are now members of the larger community.

In 2001, the government announced plans to build on the Taipei Mass Rapid Transit System(MRT). The MRT goes directly over Lo-Sheng Sanatorium. To date, 70 percent of the buildings have been demolished. The government built some temporary housing and later an eight-floor hospital. This concrete structure was unfit for our elderly residents used to having access to the land for gardening and farming. This dramatic change in living has probably contributed to the death of 150 residents, leaving only 280 from Lo-Sheng sanatorium still alive. We continue to struggle for human rights, heritage preservation, social concern, and dignity.

In October 2005, a judgment from the Tokyo court ruled that the Japanese government must provide compensation to the current and ex-residents of Lo-Sheng Sanatorium. The government in Taiwan used this as an opportunity to simply pay us and ignore the violation of our civil and human rights. The insensitivity of the Taiwanese government united the residents of Lo-Sheng Sanatorium to fight for lifetime health care and the preservation of the sanatorium as a national memorial.

On July 18, 2008, the "Hansen's disease Patients Human Rights Protection and Compensation Act" was passed by the Legislative Yuan (the Diet of Taiwan). With this Act, the Taiwanese government agreed to apologize for their past mistakes on the segregation of persons with HD, and to provide compensation for this practice that was originally started during the Japanese occupation.

The government of Taiwan has not acknowledged that persons with HD were treated unfairly, although they do recognize that stigma exists. They still refuse to accept that this stigma has any correlation to health policies of the past.

The signing of this ACT was a triumphant moment for the thousands who were admitted to the Lo-Sheng Sanatorium since the 1930's. We believe that this is a new page in the history of HD.

With the emotional and financial support of many, we have won part of the battle with this Act. However, the MRT continues moving forward and the government's desire to demolish the sanatorium has not ended.

Those of us who have lived at Lo-Sheng Sanatorium are grateful to the many who have supported us including IDEA (Integration, Dignity and Economic Advancement), CHORE (Center for Housing Rights and Evictions), NIPPON FOUNDATION, ILA (International Leprosy Association), ILEP (International Anti Leprosy Organization), WHO (World Health Organization), non-government organizations in Japan and Korea, and many individuals from throughout the world. We wish to do our best to achieve "A World Without Leprosy".

Lee, Ten-Pei (李添培)

IDEA Taiwan, President.

Address : Lo-Sheng Sanatorium, 796 Jhongjheng Rd.

Sinjhuang City , Taipei County , Taiwan

Tel : +886-9-68464099 Fax : +886-2-86775887



Pamela Parliapano who took this photo described the scene as, "...a story about brave people...who march for their right to stay in their homes, ...and have fought all the way to the legislature." The banner reads, **WELCOME TO LE-SHENG SANATORIUM. THE GOVERNMENT CAN COMPLETE A SECTION OF THE SUBWAY AND BY PASS OUR HOME.**

Douglas Soutar, General Secretary, International Federation of Anti Leprosy Associations
Leprosy and Human Rights

On the 18th June the United Nations Human Rights Council unanimously adopted a resolution on “The elimination of discrimination against persons affected by leprosy and their family members.” This historic resolution was sponsored by 59 member states and made specific reference to key earlier documents, namely the Universal Declaration of Human Rights (1948) and the International Covenant on Economic, Social and Cultural Rights (1966).

The Council called upon Governments to take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members and requested the Office of the High Commission for Human Rights (OHCHR) to collect information on the measures that Governments take to eliminate discrimination against persons affected by leprosy and their family members and to submit a report to the Council. It further requested the Human Rights Council Advisory Committee to formulate a draft set of principles and guidelines to eliminate discrimination against persons affected by leprosy and their family members, and to submit it to the Council for its consideration by September 2009.

This resolution is very important and all should be encouraged to pursue its follow-up and implementation. However, leprosy has traditionally been seen as a disease apart and there are parallel arguments that rights based approaches to health and development should be pursued for the benefit of *all* people, including those affected by leprosy.

Since people affected by leprosy should have the same human rights as all people, it is appropriate to make greater use of the International Covenant on Economic, Social and Cultural Rights (1966). Almost all the articles of this Covenant can be seen to remain unfulfilled and unrespected for people who have been affected by leprosy. Its articles cover self determination, economic and social and cultural rights, right to work and fair remuneration, protection of the family, adequate living standards, physical and mental health, education, participation in cultural life, and access to the benefits of scientific progress.

In 2008 the UN Convention on the Rights of People with Disabilities entered into force following its adoption and ratification by the requisite number of member states. This Convention too, represents a major new international legal instrument and with its greater focus on inclusivity in development, is of critical importance in pursuing the rights of all persons with disabilities, including those affected by leprosy.

The WHO Global Strategy on Leprosy highlights the importance of social justice and equity and stresses that this must be integral to all leprosy work including approaches to preventing disability, stigma and discrimination. Specific practical strategies are therefore needed to ensure States meet their obligations to respect, protect, fulfill and promote the rights enshrined in these various Conventions and Covenants including the latest UNHRC resolution to end leprosy related discrimination.

The 17th International Leprosy Congress in Hyderabad in 2008 highlighted the increasing importance being attached to the issue of leprosy and human rights with workshops, presentations and plenary sessions on the topic. And yet, stigma and discrimination remain widespread for people affected, their families, and communities. Negative attitudes are perpetuated through ignorance, fear, laws, the media and social exclusion. Health workers, in spite of their knowledge, may often be the worst offenders. In many countries laws remain citing leprosy as grounds for divorce, non inheritance or travel restrictions.

Practical Approaches

Education: Educating people affected by leprosy and their communities about their rights, facilitating social mobilization and enabling communities to advocate for legislation in their countries are some practical activities that can be undertaken.

Better use of media and language: The media in all its forms is still not used enough to promote and reinforce positive attitudes. We need to continuously challenge the unacceptable and stigmatizing labels which persist and promote more inclusive terminology and appropriate language.

Legislative reform: Collection of data on existing legislation, both good and bad, might give a focus for future campaigns for change.

Working together: All people who are marginalized, disabled or oppressed, *including* those affected by leprosy, need to engage more broadly with each other in order to promote the rights of all.

Promoting inclusivity: All organizations involved with leprosy work need to be inclusive of persons affected in their policy development processes.

Integration of leprosy treatment into the general primary health services and integration of leprosy rehabilitation and prevention of disability programmes into broader community based rehabilitation programmes are prerequisites for sustainable leprosy control. Likewise, work to uphold the human rights and dignity of people affected by leprosy needs to be integrated into the growing efforts, both globally and locally, to pursue integrated and inclusive rights-based approaches to health and development for all.

AN APOLOGY LONG OVERDUE By Valerie Monson

On April 30, 2008, the Hawaii State Legislature took an important and unprecedented stand when it adopted SCR 208 – a Senate Concurrent Resolution that acknowledged the people of Kalaupapa and their families for the sacrifices they have made and apologized for any undue pain that was caused by the harsh restrictions that were used to separate people with leprosy from the general public.

It is believed to be the first time that the Hawaii Legislature has apologized to a group of people for policies of past governments.

This resolution recognizes the estimated 8,000 people sent to Kalaupapa from 1866 to 1969 who left all that was dear to them to be isolated on the remote Molokai peninsula because they were led to believe that they were a threat to the public health. Most people diagnosed with leprosy (now called Hansen's disease) willingly left their families and relocated to Kalaupapa because they did not want to spread the disease. In other words, the people of Kalaupapa cared more about their fellow Hawaii residents than they did about themselves.

The idea for such a resolution began 30 years ago when Paul Harada, one of Kalaupapa's most respected leaders, was testifying before the Hawaii State Legislature about the need to save Hale Mohalu, the Pearl City facility established in 1949 as an alternative to Kalaupapa and a place where Kalaupapa residents could stay when they needed medical treatment available only on Oahu. Despite the valiant efforts and protests of Kalaupapa residents and their supporters, Hale Mohalu was eventually razed.

At one of those Legislative hearings regarding Hale Mohalu, Mr. Harada said that while the people of Kalaupapa have often thanked the State of Hawaii for providing for their care, he was upset that the State and the people of Hawaii had never thanked the people of Kalaupapa for all that they had sacrificed for society.

Mr. Harada continued to share those thoughts over the years. Finally, last December, Mr. Harada's younger brother, Glenn Harada, suggested asking the State Legislature to adopt a resolution that would acknowledge the Kalaupapa residents. Glenn Harada is a member of the Board of Directors of Ka 'Ohana O Kalaupapa, a nonprofit organization made up of Kalaupapa residents, their family members, descendants, friends and others who have an interest in the community.

Sadly enough, Paul Harada died on Jan. 4, 2008. In his memory as well as the memory of other Kalaupapa residents who had died and in honor of the remaining 28 Kalaupapa residents, the 'Ohana decided to carry on with plans for the resolution.

Senator J. Kalani English, who represents Kalaupapa, offered to introduce the resolution and Senator Roz Baker, who used to represent Kalaupapa when she was in the House of Representatives, asked to co-sponsor. On the House side, Representative Mele Carroll, whose district includes Kalaupapa, said she would pursue a concurrent resolution.

A community meeting was held at Kalaupapa in early February to review a draft resolution. Residents were moved and tears flowed as the resolution was read, triggering old memories of separation and discrimination that have not faded with the years. Some residents at the meeting felt that an apology was due to them and to those who went before them and experienced even more hardships and injustices. After the meeting, others in the community said they felt the resolution would not be meaningful without an apology.

In mid-August, Senator English traveled to Kalaupapa and read the resolution to the community. He also read the resolution to Kalaupapa residents receiving medical attention at Leahi Hospital on Oahu.

News of the landmark Resolution was reported in the major Hawaii daily newspapers as well as newspapers across the Mainland.

COMMITMENT TO INFLUENCE CHANGE

By Doe Sung Lim

I was born into a poor farmer's family as the eldest son of five children in a small town in Haenam County, North Jeolla Province in Korea on the 17th of July in 1949. My family was already very poor, and, to make things worse, my father passed away when I was only 16, leaving a pregnant wife and 5 children behind. Aggravating the situation was the fact that I was diagnosed with Hansen's disease (HD), which was very much feared and considered incurable at that time. I do not know the exact cause of the disease, but my environment of poverty and poor nutrition might have been contributing factors. Out of desperation to isolate myself from the outside world, at age 18 I went to an island called Sorokdo where persons affected by HD were separated and quarantined. After two years of hospitalization and treatment in Sorokdo, I left the island cured of the disease.

All I could do after I returned from the island was to follow in the footsteps of those who had been cured from Hansen's disease. At that time, persons affected by Hansen's disease lived in makeshift houses at the foot of the Bong-Hwa Mountains. I was not allowed to return to my hometown, so I had no choice but to live with the patients in the place where no one knew me. During the summer months, I cut trees and cleared forests to grow crops in a ravine in Inje County, Gangwon Province. During the winter months, I would survive by begging for food. That is how I lived from my late teens to early 20's.

Despite such hardships, I did not let my hopes die. Maybe that was why I was able to see a ray of light in my life, falling in love and getting married to a beautiful girl who was healthy and free of the disease. After our marriage we lived in one of the settlements for HD patients where I became a leader of the Gyung-Chan Resettlement Village in my late 20's

With increasing awareness of the world around me, I realized that eliminating the discrimination against Hansen's disease patients in our society is a way to reclaim the patients right to live life as a human being. So I decided to dedicate myself to the human rights movement for patients.

I have devoted most of my adult life to forming a Christian youth association with young Hansen's disease patients across the country so that they can have opportunities to secure a formal education and attend religious training.

In 2003, I was elected President of the Hanvit Welfare Association which was established to promote the rights and welfare of Hansen's disease patients. Representing 20,000 Hansen's disease patients and 100,000 family members in Korea, I have and will continue to strive to make a difference in their lives. To help protect the human rights of patients who suffer from serious discrimination, I have held discussion forums with scholars, and appealed to government organizations and law makers. Additionally, I initiated efforts to have persons affected by HD to receive compensation from the Japanese government for its forceful segregation of Hansen's disease patients in Sorokdo during the Japanese colonization of Korea. These efforts finally proved successful when the Japanese government agreed to grant compensations. Another victory came in September 2007 when the National Assembly of Korea enacted a special law for HD patients.

On May 30, 2008, I was elected to Korea's National Assembly as a member of the Grand National Party. Knowing better than anyone else about the life of the less fortunate, I embarked on a quest to make Korea's social safety net strong enough to support the physically and mentally challenged, the elderly, children, low-income families and others who are among the least privileged in our society. Based on my experience of living in the darkest and the most marginalized conditions, I am committed to making Korea a kinder and more gentle nation for all.

As a lawmaker, I have promised not to be embroiled in power struggles or political strife. I am committed to work hard in order to influence the formulation of policies beneficial to all persons with special needs. I plan to devote myself to making a society where principles and common sense work, the honest are not short-changed, and the disabled no longer suffer from social discrimination and prejudice.



Mr. Lim visited a hospital for HD patients together with the Minister of Health, Welfare and Family

Two weeks after being elected to the National Assembly, I introduced a resolution to establish an ad-hoc committee for the disabled. This ad-hoc committee can serve as a forum for the disabled and others who are experiencing social discrimination, unfair institutionalization and practices that do not address patient rights to create a ‘world without discrimination.’ When approved by the National Assembly, this committee can serve as a communication channel that will allow the voices of the disabled to be heard and hopefully initiate change to enhance human rights.

On June 26, 2008, I held a public hearing aimed at introducing and passing five legislative bills designed to help patriots and veterans live a stable life and raise their profile so that the wider general public can acknowledge their contributions. I have believed that our future generations will be motivated to step forward in times of national crisis especially after they have been made aware of the sacrifices made by others.

Along with such efforts, I am actively participating in the legislative actions to correct unfair practices in the health care market and serve on the International Board of IDEA (Integration, Dignity and Economic Advancement), a 20,000 member organization of persons affected by HD headquartered in the United States. Many other changes can be made with the collective efforts of others, especially among persons affected by Hansen’s disease around the world.

Grassroots Work in Ghana By Kofi Nyarko, Board Member, IDEA

I am Kofi Nyarko. I am a member of the Board of Directors for IDEA International*. I have been involved with IDEA almost 14 years now. I mostly do grassroots work. I choose to do this kind of work because I was rejected when I had leprosy. Now I am someone who can help others overcome their situation.

I contracted leprosy when I was seven years old. Now I am 37 years old and married to Mrs. Lucy Nyarko. God has blessed us with three children, two boys and one girl. I am Director of a school in Ghana for children with special needs.

IDEA has changed many lives here in Ghana—many people who have lived in leprosy communities for 5, 10, 22, 45 and even 51 years. Many chose leprosy communities as their homes because of stigma some years ago. I can say in Ghana with the support of IDEA, many of the people have now returned to their home town and are enjoying life with their entire community and their families. Some were given children to stay with them when they went home, to show how much they were accepted back into society. Some were given responsibilities in their towns to show that they were really needed in the community. With IDEA many people have learned that they can do something to support our nation.

When I started the work of IDEA, I learned here in Ghana that the radio stations and the television stations alone will not solve the problems of the people who have had leprosy. So I planned to move from village to village, town to town and then house to house to let people hear what IDEA offers for the whole society.

IDEA has not only helped the people who had leprosy in Ghana, but it has also helped those who have HIV, because they too were facing stigma. Now I can say that the people who had leprosy and HIV can work without discrimination or they can choose to go to any school they want to. All this happened in Ghana because of IDEA. IDEA has reached a point where our government has given free education to all of the children in Ghana from primary one to primary six.

The grassroots work for IDEA continued in countries like Switzerland where I spoke to the 57th Session of the Sub-commission on Human Rights. I also had the opportunity to meet with people of Ethiopia and attend an empowerment workshop in Kenya. On two IDEA Expert Exchanges, I was able to establish IDEA branches in DR Congo and Mali.

It is very good that IDEA was established for us in order to let people hear our voices.

*International Association for Integration, Dignity, and Economic Advancement

IDEA is the first international advocacy organization whose leadership and membership is largely composed of individuals who have personally faced the challenges of leprosy. Founded in 1994, IDEA is an international network of support with branches in 22 countries.

HANSEN'S DISEASE CLINICS

BOSTON HD CLINIC

Lahey Medical Center
41 Mall Road
Burlington, MA 01805
PH: (781) 744-5670
Fax: (781) 744-5687
Primary Physician - Dr. Samuel Moschella
email: samuel.l.moschella@lahey.org
Public Health Nurse - Ms. Stephanie Burns, R.N.,
D.N.C.
email: stephanie.a.burns@lahey.org

CHICAGO HD CLINIC

University of Illinois
College of Medicine at Chicago
Dept. of Dermatology, (MC 624)
808 S. Wood, RM 376 CME
Chicago, IL 60612
PH: (312) 996-0734
Fax: (312) 355-0870
Primary Physician - Dr. Carlotta Hill
email: chhill@uic.edu
Public Health Nurse -
email:

LOS ANGELES HD CLINIC

LAC+USC Medical Center
Attn: Section of Dermatology
Room 8440
1200 North State Street
Los Angeles, CA 90033
PH: (323) 226-5240
Fax: (323) 226-2654

Primary Physician - Dr. Thomas Rea
email: rea@hsc.usc.edu
Public Health Nurse - Ms. Helen Mora, R.N.
email: hmora@lacusc.org
Occupational Therapist - Rob Jerskey
email: robjerskey@yahoo.com

MARTINEZ HD CLINIC

Contra Costa Regional Medical Center
Outpatient Specialty Clinic
2500 Alhambra Avenue
Martinez, CA 94553
PH: (925) 313-6726
Fax: (925) 370-5279
Primary Physician - Drs. Sutherland/Saffier
Dr. Sonia Sutherland/*email: sesutherland151@pol.net*
Dr. Ken Saffier/*email: ksaffier@yahoo.com*
Public Health Nurse - Ms. Elise Judy, R.N.
email: ejudy@hsd.co.contra-costa.ca.us

Community Health Worker - Maria Soto Phone:
(925) 370-5868

MIAMI HD CLINIC

Jackson Memorial Hospital
1611 N.W. 12th Avenue
ACC East - 2nd Floor
Dermatology - Hansen's Clinic
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 - Ms. Gail Chepenik, R.N.
email: gchepenik@um-jmh.org

NEW YORK HD CLINIC

Bellevue Hospital Center
Department of Dermatology
Room 17-N-7
462 First Avenue
New York, NY 10016
PH: (212) 562-6096
Fax: (212) 263-6423
Primary Physician - Dr. William Levis
email: William_Levis@yahoo.com
Public Health Nurse - Ms. Aloys Cabrera, R.N.
email: cabreraa@bellevue.nychhc.org
Physical Therapist - Mr. Louis Iannuzzi, P.T., C.Ped.
email: lnuzzi@yahoo.com

PHOENIX HD CLINIC

Maricopa County Health Department
1645 East Roosevelt Street
Phoenix, Arizona 85006
PH: (602) 372-6661
Fax: (602) 506-6615
Primary Physician - Dr. Ronald Pust
email: rpust@email.arizona.edu
Public Health Nurse -
Physical Therapist - Tracy Carroll, MPH
email: tcarroll@email.arizona.edu

SAN DIEGO HD CLINIC

North Central Public Health Center
2440 Grand Avenue
San Diego, CA 92109
PH: (858) 490-4400
Fax: (858) 490-4405
Primary Physician - Dr. T. O'Grady
email: togrady@ucsd.edu
Public Health Nurse - Ms. Carmen Rodriguez, R.N.
email: carmen.rodriguez1@sdcounty.ca.gov

SAN JUAN HD CLINIC

University of Puerto Rico
Medical Sciences Campus
School of Medicine - Dept. of Dermatology
P. O. Box 365067
San Juan, PR 00936-5067
PH: (787) 765-7950
Fax: (787) 767-0467
Primary Physician - Dr. Pablo Almodovar
email: rcmdermatol@rcm.upr.edu
Public Health Nurse - Ms. Sonia Santos-Exposito,
R.N.
email: smsantos@rcm.upr.edu

SEATTLE HD CLINIC

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

Primary Physician - Dr. James Harnisch
email: jpharnisch@comcast.net
Public Health Nurse - Ms. Virginia Ouellet, R.N.
email: ouellv@u.washington.edu
Physical Therapist - Tom McClure, PT, CHT
email: tmcmtpt@u.washington.edu

TEXAS HD CLINICS

Department of State Health Services
Hansen's Disease Program
P. O. Box 149347
Austin, TX 78714-9347
PH: (800) 252-8239 Option 5
Fax: (512) 458-7451
Officer Administrator: Kirbi Woods
email: kirbi.woods@dshs.state.tx.us
Ms. Linda Brown, Program Director
email: lindaj.brown@dshs.state.tx.us

Dallas County Department of Health & Human Sciences
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: jack.cohen@utsouthwestern.edu
email: Sharon.nations@utsouthwestern.edu
Public Health Nurse - Ms. Nancy Bernstein, BSN, RN
email: Nbernstein@dallascounty.org

Houston Hansen's Disease Clinic
Northside Health Center
8504 Schuller Street
Houston, TX 77093
PH: (713) 794-9078
Fax: (713) 384-7741
Physician - Dr. Terry Williams
email: Tewill2391@aol.com
Public Health Nurse - Joan Taylor, R.N.
email: Joan.Taylor@cityofhouston.net

Texas Center for Infectious Disease
2303 S. E. Military Drive
San Antonio, TX 78223
PH: (210) 534-8857 ext. 2327
Fax: (210) 531-4508
Physician - Dr. Robert N. Longfield/Dr. Adriana Vasquez
email: robert.longfield@dshs.state.tx.us
email: adriana.vasquez@dshs.state.tx.us

Public Health Nurse - Ms. Debbie Mata, R.N.
email: debbie.mata@dshs.state.tx.us

South Texas Health Care Center
OPCL
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 - Vacant

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 Armauer Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without 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 dapson. 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"

VOITURE NATIONALE

777 North Meridian St., Suite 204
Indianapolis, IN 46204-1065

NONPROFIT ORG.
U.S. POSTAGE PAID
RICHMOND, IN
PERMIT NO. 1002

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.

