

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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GLOBAL FORUM OF PEOPLE'S ORGANIZATIONS ON HANSEN'S

Manila, Philippines, September 7 - 10, 2019

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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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GLOBAL FORUM OF PEOPLE'S ORGANIZATIONS ON HANSEN'S DISEASE

Summary, Conclusions and Recommendations

The Global Forum of People's Organizations on Hansen's Disease was held in Manila from September 7 to 10, 2019.

Organized by The Nippon Foundation and Sasakawa Health Foundation, the Global Forum brought together representatives of 23 People's Organizations from 18 countries. Over 80 people attended, including observers and resource persons.

It followed three regional assemblies held in Africa, Asia and Latin America/Caribbean earlier this year that laid the foundations for the Global Forum and helped to shape its agenda.

The Global Forum provided a platform for People's Organizations to share plans, ideas and experiences, learn from each other, receive training aimed at strengthening their capacity, make recommendations and provide a "people's perspective" on Hansen's disease to international organizations, national governments, partner institutions, media and other stakeholders.

The title of the Global Forum took into account the concerns and recommendations from the African and Latin American/Caribbean assemblies regarding terminology and self-identification. This resulted in using the term Hansen's disease and not leprosy, and People's Organizations on Hansen's Disease rather than Organizations of Persons Affected by Leprosy.

Over four days, the Global Forum addressed a number of themes that People's Organizations have identified as important to them in terms of their organizational capacity, sustainability, and capability to meet the expectations of the people they represent.

There were training workshops on social enterprise, fundraising, management and networking. There were plenary sessions on human rights, sustainability and public health, followed in each case by group discussions.

There was also a proposal to organize a joint campaign for World Leprosy Day 2020.

The Global Forum underscored the fact that Hansen's disease is not just an issue of health but an issue of human rights. Efforts against Hansen's disease will not be successful if they only treat the bacterial causative agent and do not address the disease's physical, psychological, social and economic consequences.

Although the disease is curable, it is still stigmatized. The continuing stigma remains a barrier to case detection, treatment and inclusion.

The Global Forum recognized that addressing issues of clean water, nutrition, good sanitation, housing, education and dignified work—issues that go beyond health—is critical to a comprehensive strategy against the disease.

The Global Forum noted that in a time of lowered government priorities on Hansen's disease and the non-uniform distribution of cases, empowered People's Organizations on Hansen's disease are needed more than ever: to advocate for sustained Hansen's disease services that deliver accessible quality treatment and rehabilitation; and to promote dignity, equality and respect for human rights.

During the four days of discussions, participants in the Global Forum recognized that they have a responsibility not only to represent their organizations, but also all those who do not have a voice and were not present at the Global Forum.

Against this backdrop, the Global Forum came up with a number of conclusions and recommendations, as follows:

Conclusions and Recommendations

Hansen's disease is more than a disease caused by a bacterium. Poverty, institutional, social and political neglect, complacency and the structural invisibility of vulnerable populations contribute to the perpetuation of Hansen's disease.

There are still gaps in knowledge about Hansen's disease. More investments are needed to research and develop new diagnostic tools and effective anti-microbial treatments and for management of Hansen's disease reactions, and to develop new models to manage social aspects of the disease. Greater commitment from government, academic institutions and industry is needed. National programs should strengthen timely case detection, disability prevention and rehabilitation during treatment, and develop

services for care after cure to include psychological, social and economic rehabilitation.

The UN Principles and Guidelines for the elimination of stigma and discrimination against persons affected by leprosy and their family members should be widely disseminated and implemented by governments and civil society.

All remaining discriminatory laws and practices must be abolished. Although that would represent important progress, it would not be enough for the enforcement of human rights, for which affirmative and reparation measures and policies are needed.

Full and impactful participation of People's Organizations in policy-making processes concerning Hansen's disease must be assured.

Special attention must be given to the situation of vulnerable populations with Hansen's disease—especially women, children, immigrants, refugees, the elderly and the homeless—and those living in geographically inaccessible areas.

Governments should develop measurable action plans recognizing that not only the health ministry but other ministries and agencies must be involved collectively in resolving Hansen's disease issues.

People's Organizations should strengthen existing networks and create truly functioning regional and global networks. NGOs and governments should strive to support the formation and sustainability of these networks.

People's Organizations must actively advocate for quality Hansen's disease services within an integrated health structure and system and through their committed participation help ensure the sustainability of the Hansen's disease program.

Governments and other partners should be open and willing to fund projects that address the sustainability of People's Organizations in recognition of the contribution these organizations can make.

As a step toward reducing stigma and discrimination, there was strong support from some quarters of the Global Forum for the term Hansen's disease to be adopted as the official term for leprosy worldwide.

Although not on the formal agenda of the Global Forum, the participants recognized the importance of preserving Hansen's disease history and heritage as a record and a guide for future generations.

Participating People's Organizations (in alphabetic order)

Bangladesh -Bogra District Leprosy & Disability Development Organisation
Bangladesh -DAPA (Disadvantaged People's Association)
Brazil -Morhan (Movement for the Reintegration of Persons Affected by Hansen's Disease)
China -HANDA Rehabilitation and Welfare Association
Colombia -Felehansen
DR Congo -OPALCO (Organization of People Affected by Leprosy in Congo)/IDEA Congo
Ethiopia -ENAPAL (Ethiopian National Association of Persons Affected by Leprosy)
Ghana -IDEA Ghana
India -APAL (Association of People Affected by Leprosy)
India -Children United for Action
India -Samuthhan
India -IDEA India
Indonesia -PerMaTa Indonesia
Kenya -IDEA Kenya
Mozambique -IDEA Mozambique
Myanmar -MAPAL (Myanmar Association of Persons Affected by Leprosy)
Nepal -IDEA Nepal
Niger -IDEA Niger
Nigeria -IDEA Nigeria
Philippines -CLAP (Coalition of Leprosy Advocates of the Philippines)
Philippines -IDEA Philippines
Sri Lanka -IDEA Sri Lanka
Tanzania -TLA (Tanzania Leprosy Association)

Polio and Hansen's Disease - A comparison of Far-Reaching Effect From a Patient's Perspective By Cheryl Jannick

It is funny how when you get older you see things in such a different light. You reflect back on your childhood and begin to think about how your parents must have felt while going through life and handling daily circumstances. How you never really have control over most things and have to adjust your life path as these circumstances occur.

One time in particular thoughts of this nature occurred to me. Joe and I were attending the Friday night banquet at a National Promenade/Rendezvous. As is customary, the Americanism winner was introduced and gave a speech highlighting his or her circumstances that prompted this most prestigious award. We usually sit through a presentation of previous military service or community service and when the banquet is over everyone rushes up to shake the award winners hand and congratulate the celebrity. This particular year, the Americanism winner just happened to be Jose Ramirez Jr, someone that I had never heard of before. As he started to speak he explained how important the Carville Star program is to him and others like him. Jose was diagnosed with Hansen's disease in 1968 when he was just 20 years old. He was just beginning his life, with plans for continuing his education and hopes of marrying his childhood sweetheart Magdalena. After his diagnosis, Jose was taken from his new home in Laredo, Texas, in the middle of the night by a hearse to his new home in Carville, LA. Even in 1968 the stigma of the big "L" (Hansen's disease) struck fear in his parents who believed his illness was some kind of punishment for their unknown sins. Jose did not let Hansen's Disease stop him. While at Carville he earned a degree in Social work and travels the world educating people about Hansen's Disease and advocates for an end to the term "leper".

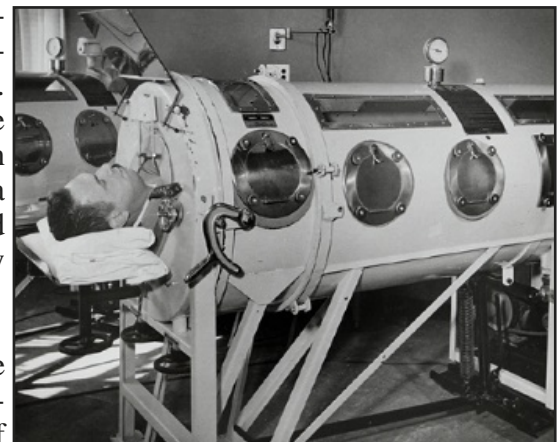
As Jose continued with his story I started to cry thinking about how hard it must be for parents to watch their sick child and have absolutely no control over what is happening to them. When Jose was finished speaking and the banquet concluded very few people approached him to congratulate him. I can't help but wonder even though many years have passed, and his disease is controlled by medication, the stigma still exists. I rushed up to him and his wife and hugged him crying the whole time, identifying with the stigma of a misunderstood disease.

Looking back on that day, I realize my tears were for my own parents who at just 23 and 24 years old, with a 4 year-old son and an 18-month old daughter. Their daughter had just been diagnosed with Polio, at that time a little known disease.

Leprosy is an infectious disease that causes severe, disfiguring skin sores and nerve damage in the arms, legs, and skin areas around the body. Outbreaks of leprosy have affected, and panicked, people on every continent. The oldest civilizations of China, Egypt, and India feared leprosy was an incurable, mutilating, and contagious disease. However, leprosy is actually not that contagious. You can catch it only if you are susceptible to the disease and come into close and repeated contact with nose and mouth droplets from someone with untreated leprosy.

The Polio virus is spread from person to person by contact with infected secretions from the nose or mouth or by contact with infected feces. It usually enters the body when the person ingests contaminated food or water or touches the mouth with contaminated hands. There is no drug that can cure polio once a person is infected. Individuals are made as comfortable as possible, with bed rest, pain-relieving medications and hot packs to help relieve the pain of extreme muscle tightness. Some need assistance with breathing, such as supplemental oxygen or a ventilator. During the epidemics of the 1930s, 1940s and 1950s, some patients with serious breathing problems were placed in an "iron lung," a cylindrical chamber that surrounded a patient's body from the neck down, which used rhythmic alterations in air pressure to force air in and out of the individual's lungs. While in the "Crippled Children's Home" in Toledo Ohio I remember being wrapped in hot wool packs. I remember the loud, scary noise the iron lungs made. The children in them would have a mirror over their head so they could see around the room and visit with the other children. When first diagnosed and hospitalized I was in quarantine and had to see my parents through a large window. Visits were kept to once a week to make it easier for us to adjust to the isolation. I remember crying when mom and dad left but after a short time I was okay. I can't imagine how difficult that was for my parents.

What is polio? Polio (short for poliomyelitis, once called infantile paralysis) is a disease that can infect the central nervous system (brain and spinal cord) and cause lasting disabilities in a small number of infected individuals. It is caused by any of three types of



polio viruses. Polio infection is most common in infants and children, but young adults and some older people get it, too.

Up to 95 percent of individuals with a polio infection have no symptoms. A small number (4 to 8 percent) have mild symptoms, such as a sore throat, headache, malaise, upset stomach and low-grade fever. These individuals generally recover completely within a week.

However, from the digestive tract, the virus can get into the blood stream and be carried to the central nervous system. About 1 to 2 percent of infected individuals develop a high fever, meningitis, stiff neck and limb pain. These individuals generally recover completely, usually within 10 days.

In fewer than 1 of every 100 infected persons, the virus attacks nerves inside the spine that send messages to muscles in arms, legs and other areas. This can result in partial or complete paralysis. If the virus gets into the brainstem (bulbar polio), muscles needed for breathing, swallowing and other vital functions become paralyzed, and the person may die.

In its natural course, Polio has three major states:

- The Acute Illness lasting 1-3 weeks,
- The Recovery Stage, extending over 6-12 months,
- The Chronic or Residual Stage

The acute illness is further subdivided into Minor and Major.

The Minor illness is characterized by nonspecific symptoms similar to those of many other infections such as fever, general malaise, headache, generalized aches and pains, nausea and vomiting. After 1-3 days the patient may temporarily improve and then become sick again.

The Major illness in its pre-paralytic stage is marked by the same symptoms as the minor illness, but in a more severe form, and by the appearance of additional and more specific signs and symptoms. These include neck and back stiffness, and pain and tenderness of muscles accompanied by muscle spasms which can last for a long time. After 1-2 days, the paralytic state sets in, becoming fully developed during the following 1-2 days. The paralysis is of a flaccid type with no sensory loss. The limbs and trunk muscles become paralyzed in varying combinations and to varying degrees. General symptoms and muscles usually begin to improve from about the second week after the onset of the illness. During the third week the general and local symptoms subside. There is some clinical evidence to suggest that muscles that are exercised during the acute state of the disease are more prone to paralysis. It is therefore prudent to insist on complete bedrest during this period and to ensure proper positioning of the limbs, to alleviate muscle spasm and pain.

In the Recovery Stage muscles begin to recover power and function directly after the acute illness. Between 3 and 6 weeks after the onset of the disease, the final outcome can be determined. Muscles that show neither movement nor strength at 6 weeks will remain totally paralyzed. Muscles with a little movement or strength will improve but remain weaker than normal; and muscles that can be moved by the patient will acquire increasing strength. Muscle recovery is quick during the first 6 months after illness and much slower from then on. By the end of the first year, muscle recovery is practically complete. Any residual muscle paralysis at the end of the first year after the onset of the disease may be regarded as permanent disability.

After the active stage of the disease is over, surviving nerve cells gradually send out new nerve connections to orphaned muscle cells in an attempt to take over the function of nerve cells that were destroyed. This often allows the patient to regain use of muscles and recover, partially or completely. Patients with permanent, partial paralysis are taught to use remaining healthy muscles. They generally go on to lead active lives, although some require braces and wheelchairs. . My type of polio was paralytic. I was paralyzed on my left side but recovered muscle strength in my neck and arm. I wore a hip brace for several years and graduated to a knee brace until I was in the third grade. I am amazed at the medical knowledge during the late 40's and early 50's. My polio doctors (orthopedic surgeons) performed therapy and surgeries to correct my spine curvature and a five inch difference in leg length.

Franklin D. Roosevelt developed acute symptoms of poliomyelitis while visiting his summer home on Campobello Island, New Brunswick, Canada. He was thirty-nine years old. It is believed that he most likely was infected while visiting a large Boy Scout encampment at Bear Mountain, New York on July 28, 1921. For several years after his attack of polio, FDR searched for ways to regain the use of his legs. For several winters he cruised the warm Florida waters where the sun and swimming seemed to help. He spent two summers with a doctor in Massachusetts who had devised a new set of exercises for polio patients. He had no lasting improvements from either approach. At the suggestion of a friend, FDR went to a run-down resort in Warm Springs, Georgia, to

bathe in the mineral rich waters. He was delighted to find the water was so buoyant that he could walk around in it without braces. In 1927, he purchased the resort and converted it to a water therapy treatment center for polio patients. It became the Warm Springs Foundation and, over the years, treated thousands of polio victims who went to Warm Springs, Georgia for treatment. It was believed that the naturally warm waters had recuperative powers for polio victims.

Now you have been introduced to a small history of Polio. Oh but wait, those of us that survived Polio and found our own way to function with our inabilities now find ourselves facing a new obstacle, PPS.

Post-polio syndrome (PPS) is a condition that affects polio survivors many years after recovery from an initial attack of the poliomyelitis virus. PPS is characterized by a further weakening of muscles that were previously affected by the polio infection. The most common symptoms include slowly progressive muscle weakness, fatigue (both general and muscular), and a decrease in muscle size (muscular atrophy). Pain from joint deterioration and increasing skeletal deformities such as scoliosis are common. Some individuals experience only minor symptoms, while others develop more visible muscle weakness and atrophy. PPS is rarely life-threatening but the symptoms can interfere significantly with the individual's capacity to function independently. While polio is contagious, PPS is not transmissible. Only a polio survivor can develop PPS.



In the early years, there was some speculation that the cause of PPS might be a "recurrence" of polio or reactivation of the polio virus, which is not the case. Many experts believe that the overburdened nerve cells that sent out new connections to take over for destroyed nerve cells eventually begin to fail, resulting in new muscle weakness. Other factors, including normal aging, probably also play a role.

PPS is a very slowly progressing condition marked by long periods of stability. The severity of PPS depends on the degree of the residual weakness and disability an individual has after the original polio attack. People who had only minimal symptoms from the original attack and subsequently develop PPS will most likely experience only mild PPS symptoms. People originally hit hard by the polio virus, who were left with severe residual weakness, may develop a more severe case of PPS with a greater loss of muscle function, difficulty in swallowing, and more periods of fatigue.

The polio virus has been eradicated in the US for more than 30 years. Only 3 countries in the world are not yet free of the disease: Afghanistan, Pakistan and Nigeria. Parents need to know that vaccination is the key to preventing polio from returning to the US.

Thank you for taking the journey through the history of polio with me. I feel very fortunate to have had my family to stand with me through all of my surgeries and hospital stays during my childhood. I thank them for all of the love and support given to me to make me the strong, independent woman that I am today. I thank the medical field that continues the never ending research to treat and eventually eradicate diseases like Hansen's Disease and Polio. Thank you to Jose Ramirez Jr for his dedication to educating the world about Hansen's Disease and to eradicate the stigma attached to it.

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Editor's Note: Receiving the Americanism Award from the 40&8 has been the highlight of my career especially with my wife, children and some of my siblings present. Cheryl added to the award with her embrace. Now it is time for me to pass on this unique Americanism Award to her for her own unique journey.

Listening to Wounded Bodies

By Claire Manes

A television commercial for an injectable psoriasis treatment resonates with individuals with Hansen's disease. Psoriasis, a chronic disease of the immune system, causes thick red, itchy, flaky patches or plaque to appear on the surface of the skin. In the commercial, patients with this condition look full face at the camera and challenge the viewer, "See me." Their words remind the viewer that theirs is a condition, treatable, curable, and not contagious. Although their bodies are scarred, they are not their disease. They want others to see them, hear their story, and embrace them in their personal humanity, not shun them in the visibility of their disease.

I believe that those who have endured HD, psoriasis, or other chronic conditions have something to teach us about physical and emotional pain, and also about life. Their conditions are similar to those of persons whom Arthur Frank writes about in his book *The Wounded Storyteller: Body, Illness and Ethics*. He suggests, from personal experience and countless interviews that we have much to learn from these survivors.

In the commercial for psoriasis, men and women with the condition tell their stories, reminding the viewer that a disfiguring skin condition does not define them. They dare the observer to look beyond their skin and to see them in their human dignity. People with Hansen's disease have also experienced the oppressive stigma of narratives that rendered them isolated, and feared, but they refused to be identified as "unclean," or labeled by the "L" word. They defied such narratives and told their own counter stories, becoming activists for their own humanity. Individuals with psoriasis and HD have stories to tell, and we have the obligation to listen.

In his book *The Wounded Storyteller* Frank argues for the moral responsibility of the wounded to tell their stories and for others to listen to them. He sees this communication as an ethical one. Frank offers a paradigm of three narratives: restitution, chaos, and quest that a wounded storyteller shares. He examines these stories and addresses the ways in which we can listen to them. Communication with my friends, Don and Cindy Riker, and the 1928 Carville letters from my grandfather, Edmond Landry, illustrate Frank's theory.

RESTITUTION NARRATIVE

The commercial for psoriasis treatment represents and encourages the restitution narrative. "I was well yesterday, I am sick today, but I will be well tomorrow." (77) This is the familiar and preferred story for patients as well as the medical and pharmaceutical communities. Even before treatment and cures were available for HD, patients adhered to this narrative, taking Chaulmoogra oil and enduring other treatments in a desperate hope to "be well tomorrow." In many situations the restitution narrative works. Patients do recover from illness and are well again. But there are times when restitution fails and there is no cure. This failure is discouraging for the patient, the medical community, and those who care for and about the sufferer. Often this failure creates fear, uncertainty, discouragement, chaos.

CHAOS NARRATIVE

My friend, Don, experienced long, futile, and discouraging misdiagnoses before he received the verdict that his condition was Hansen's disease. Because there is a cure for it, he accepted the restitution narrative. He would take the prescribed treatment and he would be well, but that did not happen.

He had been cured, but not yet healed. The Hansen's bacillus was killed in his system, but the dead bacilli remained in his body and his own immune system continued to fight vainly against them. The pain and symptoms he experienced even stymied specialists in Hansen's disease treatment. His journey has been longer, more uncertain, and more discouraging than he and Cindy expected. A deeply religious man who holds onto his conviction that God is in charge of his life, Don nonetheless struggles in darkness. His situation reflects the Chaos narrative of Frank. At one point Don described his experience, "I would like to hide in a hole and pull the hole in on top of myself."

His situation has challenged his trust in the medical profession and both challenged and deepened his faith. Frank says of such a chaotic condition "the modern bulwark of remedy, progress, and professionalism crack to reveal vulnerability, futility, and impotence." (97) For one caught in the chaos narrative, nothing seems to be happening; there is no sense of control, and there are no words to express the experience.

One period in my grandfather's life represents the chaos narrative. In 1923 his world changed completely. He was confined to his home for a year and a half with leprosy. He was no longer bread winner, church goer, husband, or father. His wife who was deathly afraid of leprosy requested that they live as brother and sister. Her fear carried over to concern for their two young children. His daughter, age four, and his son, age two, could visit their father in his room only under the watchful/fearful eyes of their mother or grandmother who allowed them no physical contact with their father. To me Edmond's year and a half isolation at home fits Frank's description of the chaotic narrative. Such a condition tests the wounded story teller and challenges the listener.

Listening to the chaotic body is difficult as Frank points out. It challenges our modernist notions that anything can be cured and it is a blatant reminder of our limits and mortality. The chaotic body and the chaotic narrative force us to admit that some things are horrible. As Frank notes, "All of us on the outside of some chaos want assurance that if we fell in, we could get out. But the

chaos narrative is beyond such bargaining, there is no way out.” (102) However, the chaotic body and the chaos narrative must still be heard. The person in the midst of chaos must be listened to in his inarticulate despair. Presence and acceptance are what we can offer. It is a rare gift, but it can be found.

In their chaos Don and his wife Cindy have had graced moments with an effective listener who offered healing at a deeper level even when he was stymied by Don’s symptoms. The Rikers described one such doctor as “walking with us. He sits with us, in a circle, and hears us at more than simply a clinical level. He takes time with us, modelling what it means to be a lifelong learner. He asks questions, repeats back what he has understood of our words, offers observations more than answers, admits the limits of his knowledge and ability but does not give up on us.” Don describes such a valued listener as one who “gives me time, the gift of allowing me to process out loud my experience, to find my own perspective. He creates a safe place where I am valued, respected, believed, and heard.” This presence and acceptance is a relationship of equals, patient and doctor, journeying together for mutual understanding and answers.

A 1928 letter to my grandmother from my grandfather in Carville offers another example of this present and accepting listening. Edmond remembers Dr. Sabatier, his friend and home town family doctor, who “when I had all those open tubercles, would sit in my room on my bed and scratch his arm with prickly heat on it.” There was no known cure for HD at that time. Dr. Sabatier knew that sooner or later his patient would have to be admitted to Carville. He may have had his own fears of the disease, but in one memorable moment of presence and acceptance, Dr. Sabatier sat on my grandfather’s bed and scratched his own prickly heat.

QUEST NARRATIVE

Frank notes a final level of narrative, the Quest narrative in which the wounded story teller has embarked alone on the hero’s journey and becomes a teacher for those willing to listen and learn. In the Quest narrative the ill or stigmatized person determines to “meet suffering head on... [and]to use it” (115) for himself and others. The wounded story teller assumes agency for her life and seeks to give meaning to her condition rather than succumbing to it. She has no illusions about a return to a “normal life.” Her testimony becomes a witness to the meaning and value of her life and the life of the listener. The quest narrative invites the listener to become learner, open to the lessons the ill person has to offer about “living a good life while being ill.” (156)

The lives of my grandfather, my friend Don, and other HD sufferers point to the quest narrative which is their effort to live well and ethically while being ill. Quarantined at home for a year and a half, my grandfather experienced a chaotic narrative, but in the midst of this chaos he searched for meaning to his life with leprosy. He accepted his diagnosis and chose not simply to enter the hospital but to make a meaningful life there. Only four months after his entry to Carville he formed a canteen to serve the patients and to raise money for the blind and indigent. Despite a clearly desperate time in his life in 1928, he offered himself as a specimen at a medical conference acknowledging his willingness to expose his body to the scrutiny of the participating doctors. His life became one lived for others. His service to his fellow patients made him a witness to the value of life including the lives of those marginalized in Carville.

My friend Don’s life is also a quest narrative, and in his illness he too is a witness. His passion for sharing the Word of God deepened on this journey, but his capacity was limited. No longer does he have the stamina to preach and teach publicly in his community as often as he once had. He has deferred more than once his plans to return to India to minister there. But he perseveres in finding and sharing the meaning of his current life. Living with his illness and offering his narrative has become his ministry. In his pain and darkness he plumbs Scripture for solace and meaning and shares that with his cyber community of listeners who have acknowledged the strength they receive from his words. Faith filled storyteller and faithful listeners become community seeking the deeper meaning of the life that we all share.

My grandfather and Don are only two examples of wounded storytellers trying to live a good life while being ill or isolated. It is for us as listeners to hear their stories and to learn from them. Their testimony teaches us that the meaning of our life is not in what we do but in who we are, in how we live for others. We listen to wounded storytellers to discover the value of life and the values of their lives.. We listen, too, I believe to stretch our hearts and increase our empathy. A final example from Frank’s book helps to clarify this. Gail a woman, who suffers from chronic pain, becomes our witness and teacher. She speaks because she has knowledge borne of pain. Gail distinguishes those who don’t have pain as “normal” and the medical establishment as “whitecoats.” (p. 141) She speaks as a wounded storyteller suggesting that she has something to offer us “the normals” if we but listen. I quote:

And all these people in pain... all these people suffering. We walk in different dimensions. We have access to different experiences, different knowledges. ... What would happen if we all knew what it really meant and we all lived as if it really mattered, which it does. We could help the normals and the whitecoats both. We could help them see that they’re wasting the precious moments of their lives, if they would look at us who don’t have it. I’m convinced only sick people know what health is. And they know it by its very loss. (141).

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Remembrances of my life's journey with Hansen's Disease. By Doug Blankinship

Writing this article for The Star has challenged me to be as brave and forthcoming as many fellow patients and dedicated staff before me. These individuals wrote with the purpose of educating others from around the world about Hansen's Disease and to give courage to those who are facing the ravages of this debilitating and often devastating disease. Reading past editions of The Star helped me to reflect on my experiences as a Hansen's Disease patient over the last sixty-two years and to muster the courage to share my own experiences in writing.

By way of background, my father was in the Foreign Service and we lived in Central America when I was 3 years old. Somehow, I contracted Hansen's Disease which took five or six years to be diagnosed. My father was called back from an overseas trip to take me by car to the Carville Hansen Disease Hospital near Baton Rouge, Louisiana. You can imagine how scary being quarantined at the Carville Hansen Disease hospital in Louisiana was for a ten-year-old boy. My parents were forced to leave me at the hospital and return to Washington. Dan and Mary Bailey were chosen to become my foster parents. I was lucky to have been placed with such caring and loving people. I was also lucky to witness the courageous people who were also forced to reside here in this special place where miracles happened and a special bond was ever present between staff and patients. My fellow patients' strength and courage have emboldened me throughout my life.

When my foster father Dan was diagnosed with Hansen's Disease, he was sent out of New York City via freight train on a baggage car under protection of an armed guard. His mother had been hospitalized in Hawaii with Hansen's Disease most of her life. He was raised by his grandparents and never saw his mother again. He was in his twenties when he



I became a Carville patient during my fourth grade school year

started seeing welts on his body. He recognized immediately what the skin lesions might mean and went for medical treatment. He knew all too well what the dire consequences of the disease could cause; nerve damage, disability and deformity, the irreversible hallmarks of this disease. What he did not know was that he would be treated like a convict because of the stigma surrounding this disease.

Fortunately, I was diagnosed early and was successfully treated with the multiple-drug therapy of dapsone, clofazimine, rifampicin for several decades. My skin took on a reddish tint and I had to always explain that I hadn't gone to the Caribbean during the dead of winter. I lost feeling in my right foot and consequently injured myself several times, necessitating several surgeries and many months on crutches and trips to doctors to get ulcers treated.

Back in the mid-1950's, the hospital was like the rest of the country -- segregated. However, Claudette, a young African-American several years older than me attended Sunday school with me as we were the only youth in the hospital at the time. A former missionary who contracted Hansen's Disease in China taught Sunday school in the Chapel's library. I remember so clearly that she read to us a harrowing story called *The Raft* – about American POWs who survived the Bataan Death March and were being transported to Japan when their ship was torpedoed by one of our own subs – and then they had to battle sharks until they were finally rescued. The rough similarity of the soldiers' story to the life experience of my foster father was not lost on me. What I remember even more than the book was that Dan had to argue with Claudette's family so that we could play together and not just go to Sunday School together.

While at Carville I got to know Josefina Guerrero from the Philippines. She was in the underground resistance during World War II and Josefina had smuggled messages through enemy lines and thereby saved so many servicemen's lives. She became my heroine. Consequently, the life and death scenarios in *The Raft* became that much more real for me. The randomness of tragedy felt vividly clear to me, and moreover was the heroic fortitude to persevere.

Being an adventurous boy, I was all over this hospital and would sneak into every nook and cranny. I spent many an imaginary term in the jail for unknown crimes. One time I even swam in the lake with water moccasins! On one of my adventures, I found myself in the morgue – face to face with a corpse. My first encounter with death and I can tell you it frightened me terribly. I often worried that I would not be able to leave and would wind up dead and buried in the hospital's graveyard. I would pretend to have lost my sight or had hands that were like those of older patients – deformed and useless. I missed my parents and siblings and often was lonely. My salvation was having 25 puppets which were my constant companions which enabled me to put on puppet shows to a literally captive audience.

I remember “going over the fence” to go fishing on the Mississippi and the picnics that foster mother Mary would prepare. I didn't much care for drowning worms and wasn't too excited about gutting fish. To this day I am no fan of eating fish. I remember the many long hours of looking at the flora and fauna along the Old Muddy. Maybe, that time spent exploring had something to do with my career choice of going into natural resource conservation. I would like to think that it did.

I fondly remember meeting and working with Stanley Stein on *The Star* newspaper. I helped with the printing, packaging, and distribution of the newspaper during my ten months stay at the hospital. I remember the printing press mechanical noise, the smell of the ink and machine oil. My foster mother Mary Morris (who hid her real name Mary Bailey) handled the massive distribution duties. After all the work was done, we'd head to the Canteen for hamburgers and cokes. I recall the great pleasure and pride we felt to be part of such an important task.

Stanley went on to write the book *Alone No Longer* which tells the story of how he published *The Star* newspaper to educate the world about Hansen's Disease and bring reforms within the hospital that would give dignity to the inhabitants. In his book, he also recounts how he spent thirty years in the leprosarium at Carville, Louisiana. He lost his sight and sense of touch from Hansen's Disease in the 1950s. Unfortunately, he lost his sight just a few years before the discovery of sulfone therapy that today prevents blindness caused by Hansen bacillus. When I met him, it was the first time I had been around anyone who was blind. As a ten-year-old kid I marveled at Stanley's passion and ability to complete all of the tasks required to publish *The Star* despite his blindness.

By way of background, in 1947, the Forty and Eight purchased a printing press and other equipment to help the patients carry on “their fight against the ignorance which surrounds this disease.” The Star continues to be a gift to the world to eliminate the stigma associated with Hansen’s disease.

Hansen’s Disease patients and the general public are indebted to the Forty and Eight for helping support the publication of The Star for over seventy years. The Star had a circulation of 10,000 when Stein died in 1967 and later had as many as 160,000 subscribers from around the world. The Star remains an invaluable international network to inform all afflicted with Hansen’s Disease of progress and significant events. The National Society of the Forty and Eight and the National Hansen’s Disease Programs form a great team in their mission to improve public health and to improve the quality of life for people afflicted with Hansen’s Disease.

My mother had been trained as a visiting nurse and was able to communicate with the medical staff at Carville and pushed for my early release. She had to petition the Congressional delegations from all the states between Maryland and Louisiana to get permission for my transportation by automobile through these states. In cases where she was unable to garner the permission, she drove me and a companion through the cover of darkness to bring me home.

For many years my parents and siblings (two sisters and my twin brother) were forced to hide my illness and had to basically lie about my condition and whereabouts. They had to undergo medical checkups including skin scrapings before and after I was released from the hospital. My maternal grandparents came from Oregon to Washington, D.C. to care for me in isolation at a rural house in Maryland.

My mother would fix breakfast for my siblings and father at our home in suburban Maryland and then drive for an hour to teach me using the Calvert homeschool curriculum, then rush home to feed and care for the rest of the family. My father always blamed himself for putting me in harm’s way by being in the Foreign Service and stationed in Central America. Some of his letters from years ago are replete with apologies and praise for me overcoming difficulties with Hansen’s Disease.

I am indebted to my wife of nearly fifty years for her love and steadfast care for my welfare. She has always been there for me, cautioning me about my loss of feeling in my extremities with reminders to wear shoes and be mindful of hot water and cookware.

I applaud the Daughters of Charity of Saint Vincent de Paul for being caregivers at the hospital where they’ve cared for more than 5,000 Hansen’s Disease patients for over a century. I was fortunate to maintain communication for most of my adult life with Sister Francis de Sales Provanche, one of the 112 nuns who cared for patients since Carville’s establishment. I thank her for 53 years’ service as a nurse and Medical Records Librarian and for the love she and her order showered over the patients in their life’s work. Sister Francis died in 2006 at 90 years of age.

I wish to thank Elizabeth Schexnayder, curator at the National Hansen’s Disease Museum in Carville, Louisiana [<https://www.hrsa.gov/hansens-disease/museum>]. Her professionalism and passion for her work collecting and preserving records and artifacts, telling patients’ Hansen’s Disease stories and about the hospital, is helping to dispel the unfounded myths about Hansen’s Disease and helping to erase the stigma of this Biblical age disease. I am proud to call her my friend.

Tom Adams’s Editorial Board Member Comment: Doug Blankinship was quarantined at Carville at the age of 10. For more about HD in the United States, Doug recommends Triumph at Carville (A Tale of Leprosy in America), the 2005 DVD from the Public Broadcasting Service’s Home Video Series.

International perspective on HD

By Alice Cruz, United Nations Special Rapporteur

Ms. Cruz, thank you for your participation in helping STAR readers better understand the global view on Hansen's disease. So, please share some of your personal background and role in the world of HD.

Thank you for the kind invitation to share my experience with the readers of such outstanding and landmark journal in the history of Hansen's disease. I feel honored. I was born in Portugal and my engagement with Hansen's disease began precisely there, in my home country, which fact contradicts the widespread idea that Hansen's disease is restricted to countries of the Global South. As I started fieldwork as a young anthropologist at the last Portuguese Hospital-Colony (as it was called) designed for the compulsory confinement of persons affected by Hansen's disease, my worldview changed. I realized that ordinary gestures, such as shaking hands or giving a kiss on the cheeks, meant, for persons who had experienced severe stigmatization on the grounds of Hansen's disease, the acknowledgement of their humanity. Furthermore, the selfless love I received from persons who taught me the meaning of survival and dignity in the midst of multiple discrimination transformed me deeply. From then on, I continued working with Hansen's disease for almost all of my professional life. I have done fieldwork in many countries, always engaging with social movements and grassroots organizations, whether in the health, women or indigenous people's fields. As a researcher, I have always opted to work closely with the people's struggles for dignity and tried to acknowledge people's lay knowledge as equally valid as to modern science. In 2017, I was appointed by the Human Rights Council to be the first United Nations Special Rapporteur for the Elimination of Discrimination against Persons Affected by Hansen's disease and their Family Members. My mission is to follow up and report on progress made and measures taken by States to eliminate discrimination on the grounds of Hansen's disease, to present reports with recommendations to States and to raise awareness of the rights of persons affected by Hansen's disease and their family members.

What have been your observations as you have visited many countries deemed to have a high incidence of HD?

For me, the most striking finding is the existence of a similar pattern of experience, notwithstanding the cultural differences pertaining to each regional, national and local context. There is something unique to the experience of Hansen's disease and the social responses to it. And that is what explains why people from such diverse backdrops come so easily together and recognize a common belonging between them. I witnessed this just now, at the Global Forum of People's Organizations on Hansen's Disease in Manila. There is obviously a common history of formal segregation - many countries implemented segregation as State policy for more than one century. But there is also a shared pattern of what I call informal segregation, which means exclusion from equal opportunities and outcomes, and hindered access to the goods and services of the State. This is reflected on the poor quality of health, on the institutional neglect of people living in Hansen's disease's settlements, on the exclusion from the formal work market with adverse corollaries on access to social protection and on the persistence of harmful beliefs and practices that reproduce interpersonal stigmatization on a daily basis. Notwithstanding the fact that persons affected are driven by an intense desire for dignity and make impressive and admirable efforts to achieve it on their daily lives and also to guarantee it for the new generations affected by Hansen's disease, society still puts multiple barriers to their right to claim rights.

Recently three researchers were awarded the Nobel Prize for creating a way to overcome poverty and based such on addressing self determination and self empowerment. What opportunities are lacking among persons who have experienced HD to fuel and reverse the negative images of "beggars" and thus emulate the new images of poverty?

The interesting thing about the laureated proposal for poverty reduction is that it departs from the idea that in order to tackle poverty, poverty must be disaggregated into smaller problems, which should be fully understood through experimental research. I believe this fits well the undeniable reality of the intersection between Hansen's disease and poverty. One of the problems of the responses to Hansen's disease's socioeconomic issues is that they have not been sufficiently grounded on local realities. Moreover, such responses have mainly been developed from either health or charity institutions. Now, medicalized top-down interventions on what is narrowly described as health-related stigma are poorly on evidence. They also compartmentalize the problem in a way that fails to grasp its multidimensionality. Such top/down approach usually leads to inaction. How do we overcome this when the overall reality of Hansen's disease is framed by scarce resources and lack of funding? Through participation. We need to integrate the lay knowledge of persons affected into policy-making, since they are the ones who know better

their socioeconomic reality. Empowerment should start precisely there, on a participation that goes beyond a tokenistic approach and truly incorporates persons' affected's knowledge and views. On the other hand, any intervention that does not build capacity leads, as the laureate proposal to reduce poverty demonstrated through experimental research, to diminished impact and is not transformative. So, I would say that we are in urgent need of a twofold action: recognizing people's experience as valid knowledge for designing socioeconomic measures and building capacity to ensure sustainability of the same measures. Those are, in my view, fundamental steps towards empowerment. Without socioeconomic autonomy, self-determination is not viable, and without self-determination human rights are no more than but empty words.

How do you define “quiet diplomacy” and why is this relevant in the world of HD?

Quiet diplomacy uses back channels and is done away from the media spot light. It strives at influencing decision-making through consensus building instead of posturing. The methods employed by the various Special Rapporteurs differ according to the specificity of each mandate. Many Special Rapporteurs use the time light as an important mechanism. However, in my own work I have been realizing that the most important action I can take is to generate political engagement and this is in essence an invisible work. This should be done cautiously, wisely, consistently and through personal interaction at the highest level. One of the key barriers to inclusion is institutional neglect and the mistaken ideas that Hansen's disease is a reality of the past and that is a health issue. One effective way to overcome such barrier is through quiet diplomacy.

Any thoughts on HD in five and ten years?

I agree with the importance of the efforts to achieve zero leprosy, which is the uniting goal of all the stakeholders in the field of Hansen's disease. However, we must be realistic about this target and the difficulties to reach it and keep the importance of ensuring access to the highest attainable standard of health to those who are affected by the disease as top priority. In fact, this is the top priority of the primary stakeholders, that is, persons affected by Hansen's disease. This should lead to interventions on the social determinants of Hansen's disease, to ensuring high quality medical care during treatment - including counseling and psychological care -, and rehabilitation, support services and reasonable accommodation after cure. By the same token, we shouldn't lose the focus on the importance of eliminating any discriminatory law, policy or institutional practice. And, finally, we should

strive for the creation of affirmative measures that can ensure equal and functional access by persons affected by Hansen's disease to human rights. Is this plausible as a reality for the following years? Our biggest barrier is the structural invisibility of Hansen's disease at the global and national level, including not only States, but also inter-governmental organisms and funding agencies. That is why we must apply at the global and national level the strategy known as the best for reducing stigma: giving a personal face to Hansen's disease, through participation de facto of persons affected by Hansen's disease at institutional and public settings. Only when persons affected by Hansen's disease achieve the right to a voice and to a choice, can we realistically think about zero leprosy.

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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 Amanoer 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 2016 there were 216,108 new HD cases registered from 145 countries according to World Health Organization official figures. The countries with the highest number of new diagnoses are India, Brazil and Indonesia followed by some of the African nations. More than half of all new cases of leprosy are diagnosed in India.

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. 178 new cases were reported in the U.S. in 2015. Most of the new cases were reported in Arkansas, California, Florida, Hawaii, Louisiana, New York, and Texas.

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 dapson, 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