The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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WORLD HANSEN'S DISEASE DAY

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*Reflections on HD, COVID-19,
Stigma and Journeys for Cure*

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Stanley Stein
Founder - Editor, 1941 - 1967

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease. 2.) Serve as advocate for those who have experienced or been impacted by HD. 3) Foster self-empowerment of those who have experienced HD.

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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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Nitrosamine concerns for rifapentine and rifampicin Update and FAQs

The World Health Organization responds to HD medication issues

The following is the first response in 2021 to the concerns related to one of the medications included in the Hansen's disease treatment regimen of multiple drug therapy (MDT).

What are nitrosamines?

Nitrosamines are possible human carcinogens. They may increase the risk of cancer if persons are exposed to them above acceptable levels and over long periods of time.

These impurities can be formed in some medicines during manufacturing under certain conditions. They can also be present because of contamination (e.g. from equipment, starting materials, reagents or solvents) or because of degradation. They are not expected in the vast majority of APIs and medicines. The formation of a nitrosamine impurity can be specific to the product or non-specific (for example, in the case of cross-contamination).

Nitrosamine impurities are also present in air, water, food and other products.

What if a nitrosamine impurity is detected in a medicine?

Nitrosamine impurities should be avoided in medicines, or at least controlled below a level where human cancer risk associated with the exposure is negligible.

If a nitrosamine impurity is detected in a medicine, the manufacturer needs to investigate the root cause and apply mitigation measures to avoid or minimize the exposure. Possible root causes for the formation of nitrosamines have been published recently by the European Medicines Agency and the U.S. Food and Drug Administration.

Mitigation measures may require investigation, and changes to the product. These measures may require time until they can be verified as effective, and applicable at a larger scale. This is especially true when the mechanism of nitrosamine formation is product-specific.

In cases where the levels of nitrosamines exceed acceptable limits in medicines, such products should in general not be permitted on the market. However, when considering this action, regulators must also balance the impact on the patient if the product is no longer available. This involves determining the availability of alternative treatments and the clinical impact of stopping or switching to a different treatment. In this scenario, regulators need to carefully assess the benefit/risk balance for the specific product. When the risk of not taking the treatment outweighs the risk associated with the nitrosamine impurity, regulators can accept higher interim limits for the impurity on a temporary basis, while the mitigation measures are put in place. This also requires an in-depth quality assessment and a transparent dialogue between the regulator and the manufacturer, so that the interim limit set is as low as possible, and that correct mitigation measures occur promptly.

What is WHO Prequalification Unit - Medicines Assessment Team (PQT/MED) doing regarding nitrosamine impurities?

PQT/MED called for a review on nitrosamines for all API and medicines applications in all therapeutic areas in April 2020. Companies should undertake a risk evaluation by the end of 2020.

Please refer to: https://extranet.who.int/pqweb/news/manufacturers-conduct-risk-assessments

For all new products this information will be reviewed before acceptance and prequalification of the product.

Why are there nitrosamine impurities in rifapentine and rifampicin medicines?

1-cyclopentyl-4-nitrosopiperazine (CPNP) and 1-methyl-4-nitrosopiperazine (MeNP) are the specific nitrosamine impurities that have been identified in rifapentine and rifampicin products, respectively. Based on the structure of the impurities and the key manufacturing steps employed by manufacturers, these impurities are expected to be present at varying levels in all rifapentine or rifampicin products. Mitigation measures are needed to reduce their level. These could involve additional purification steps, for example.

Is PQT/MED conducting a risk analysis for nitrosamines in rifapentine and rifampicin?

An initial benefit/risk assessment was conducted as soon as PQT/MED became aware of the presence of nitrosamine impurities in rifapentine and rifampicin products. The consensus has been that the risk to the patient associated with interruption of treatment due to product recalls or suspension of distribution far outweighs any potential future cancer risk associated with the nitrosamine impurity present in the products.

Currently, PQT/MED is conducting product specific risk analysis based on actual reported levels, taking into consideration clinical, toxicological and quality aspects of these medicines. PQT/MED is also in contact with other international regulatory agencies and professional and patient advocacy organizations regarding this issue.

What is PQT/MED specifically doing in relation to CPNP impurity in rifapentine?

Regarding TB336 (Priftin from Sanofi) please refer to our previous note:
https://extranet.who.int/pqweb/news/nitrosamine-concerns-priftin-rifapentine-update

Sanofi has informed PQT/MED that TB336 batch 9J2501 distributed to Malawi and Zimbabwe will be replaced by new batches, as requested by the Global Fund. The new batches released by Sanofi meet the CPNP temporary limit of 20 ppm as accepted by USFDA and recognized by PQT/MED. PQT/MED acknowledges that some of the previously distributed TB336 batches might contain slightly higher levels of CPNP impurity, but that this is still acceptable from the point of view of a benefit/risk assessment.

What is PQT/MED specifically doing regarding MeNP impurity in rifampicin?

PQT/MED requested all rifampicin API and medicines applicants to undertake a risk evaluation for nitrosamine impurities by end of 2020. Some of the risk assessment reports have already been submitted and PQT/MED has reviewed them. For these products, the work on mitigation measures by manufacturers has started.

PQT/MED also requested in September 2020 that all rifampicin API and medicines applicants test the MeNP impurity in a representative number of batches. Please refer to:
https://extranet.who.int/pqweb/news/nitrosamine-concerns-rifapentine-and-rifampicin

PQT/MED expects to have all rifampicin results in the first quarter of 2021, including risk assessment reports. The required testing of MeNP in rifampicin APIs and medicines will take time, because the analytical procedure must be appropriately validated and shown to be sufficiently sensitive to detect trace levels of this impurity.

For the few APIs for which manufacturers have already reported results, an interim limit is being defined temporarily for the impurity. PQT/MED is closely working with these companies to follow up on mitigation measures that should be applied as soon as possible, in order to decrease the impurity to lifetime acceptable levels.

Given the outcome of the initial risk assessment stated above and results reported so far, PQT/MED has not suspended any of the rifampicin prequalified APIs or medicines. No alert has been considered needed for the time being, and the PQT/MED's recommendation not to interrupt any rifampicin treatment remains.

PQT/MED is closely monitoring the responses related to rifampicin products and the ongoing work by manufacturers.

The ILEP Advisory Panel of Women and Men Affected by Hansen's Disease

By Zoica Bakirtzief a Silva Pereira, Amar Timalsina, Mathias Duck

The International Federation of Anti-Leprosy Associations (ILEP) came into being 60 years ago in response to the observed need for coordination of the activities promoted by the various internationally active anti-Hansen's disease organizations. Today it has 13 members active in 60 countries. More details about the work of these organizations can be found in its website https://ilepfederation.org/ .

In recent years ILEP has established its Advisory Panel of Women and Men Affected by Hansen's disease. The initiative was to hear the voice of persons who have experienced the disease from a wide range of backgrounds, personal history, and viewpoints. ILEP wants to hear the Panel about various issues pertaining to ILEP's scope of influence. The Panel provides advice to ILEP organizations on what needs to be done and how. The demands from input might come from ILEP organizations or from the Panel. The Panel also hears to the demands that come from persons affected organizations and individuals who have experienced the disease.

More specifically, in 2015 ILEP invited a small group of persons who had personal experience with the disease to conceive the terms under which the Panel would operate. The working group was composed by Khofi Nyarko from Ghana, Mathias Duck from Paraguay and Jose Ramirez from USA, and Rachna Kumari from India. As a result, in 2016, after the terms of its operation were defined, the first panel was officially selected. The first mandate was to be from 2016 to 2019, a four-year period, and its first elected members were: Paula Brandao from Brazil, Mathias Duck from Paraguay, Rachna Kumari, from India, Amar Timalsina from Nepal, and Khofi Nyarko from Ghana.

Panel members are selected from a list of appointed candidates from various Hansen's disease associations, not limited to ILEP members. Since Panel members are to represent all persons affected and organizations, not their own organization, nor their own country or themselves there is a competitive process of candidacy and selection to occupy its seven seats. ILEP partner organizations send several candidates to participate in the selection process. Before the selection of candidates for the Panel's second mandate, a decision was made to add two additional members, thus the panel would be composed of seven members from then on.

In 2020, the selection process for the second mandate, 2020-2023, was competitive. There were over twenty appointees from various backgrounds and countries running for the Panel positions. The Panel elected was presented to the public at ILEP's website https://ilepfederation.org/who-we-are/meet-the-advisory-panel/ . There are female and male representatives from where most Hansen's disease patients are from. Namely, Africa, Lilibeth Evarestus Nwakaego and Papa Mamadou Diagne, the Americas, Zoica B.S. Pereira and Mathias Duck, and South-East Asia, Rachna Kumari, Maya Ranavare and Amar Timalsina. Mathias Duck has been serving as Panel Convener and Chair but there will be an internal voting by the members to decide who shall take these positions for the next term.

The first contributions of the Panel to the Hansen's disease world should be highlighted. The main accomplishments since the inception of the Panel was the development of the ILEP policy on language, images, and communications. This policy requires that when ILEP members talk about persons affected by the disease they do so making sure they are always upholding the persons dignity. The second main accomplishment, which is still underway, is the ILEP policy of participation of persons affected in every possible avenue. Although it has not been officially approved by ILEP, participation has been taking place in its various meetings and decision-making processes. Furthermore, The Network of Nonprofit Organizations against Neglected Tropical Diseases (NNN) has used the Panel's participation policy draft in its governance, being officially approved.

In conclusion, it might be asserted that the creation of the ILEP Advisory Panel of Women and Men Affected by Leprosy has facilitated the participation of the voice of persons who have experienced the disease in policies and communications regarding them. This is a significant beginning. It is expected it shall advance further in the future fully expanding its initial accomplishments and adding new ones.

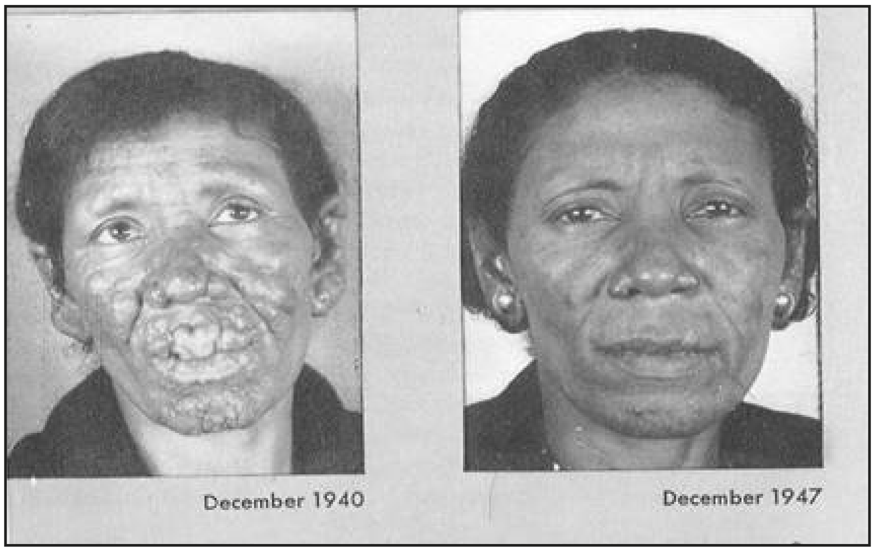
Vaccines and Treatment. The Need, the Research, the Outcome

by Claire Manes, Ph.D.

The week of December 13, 2020 began Covid Vaccine week in the United States. Large shipments of the Pfizer vaccines, packed in dry ice by agents in protective gear, have been delivered across the country, and the Moderna vaccine is destined to be available sometime after December 21. The anticipation has mounted as deaths from Covid have increased and clinical trials have reported success with vaccines. Hospital environmental services workers as well as nurses and doctors have rolled up their sleeves for the shot and the television cameras. They have been interviewed multiple times and many have admitted relief and hope that this pandemic may be ending. Science and medicine have offered hope worldwide.

In 1941 the scale was far smaller and localized in Carville, Louisiana, but I imagine the hope and anticipation were every bit as monumental when Carville residents were preparing to take a drug that perhaps held a treatment or cure for Hansen's disease. The medicine was not lifesaving; leprosy did not kill; but the residents were hoping for treatment that would finally restore their health and dignity.

Desperate for a cure, leprosy patients had ingested brews, teas, and potions of willow bark, as well as the bark of red mango trees. They had endured chaulmoogra oil despite its side effects and its limited success in curing them. Sister Hilary's experiments had made the concoction palatable but not life changing. In the mid-1930s some of the residents had submitted to fever therapy in the hopes that raising the body's temperature would kill the mycobacterium leprae which thrived in and affected the cooler areas of the body. Like so many other treatments this one proved intolerable and ineffective. Johnny Harmon described his experience with the treatment. I went "hog wild crazy and demanded they let me out" of the iron lung like machine set up for the treatment. His temperature had reached 106.8 degrees, but leprosy remained. (Fessler, 143)



Sr. Hilary Ross's dramatic photographs traced the improvement in patients who participated in Dr. Faget's drug protocol in the 1940s. The before and after pictures are witness to the "miracle at Carville." (From the collection of the National Hansen's Disease Museum, Carville, La.)

In the 1940s patients still desperate for a cure were demanding injections of diphtheria toxoids, another allegedly successful treatment for leprosy. Once again they faced disappointment. Two hundred thirty patients received the injections; not one was cured and many got worse. (Fessler, 168)

It is not surprising that in 1941 patients were skeptical when invited to participate in yet another new experiment. Dr. Guy Faget, the Medical Office in Charge at Carville had recognized the similarities between the bacilli causing tuberculosis and Hansen's disease. He wondered if Promin, a successful treatment for TB, could also work for HD.

Dr. Faget contacted the makers of Promin, the pharmaceutical company Parke Davis (now a subsidiary of Pfizer). They offered to send the doctor free samples of the medicine for his research. Success was not immediate and patients were slow to try one more experiment. However, gradually with careful monitoring and adjustments to the dosage patients saw positive results, some that patients called miraculous. Sr. Hilary's photographs chronicled the changes in patients whose features had been ravaged by the disease. Over a period of time the transformation in their appearances was startling. By 1947 the sulfone drugs including Promin, diasone and promizole were accepted and successful treatments for HD. A cure for HD would still be decades off. (Fessler,169 ff)

Sr. Hilary Ross's dramatic photographs traced the improvement in patients who participated in Dr. Faget's drug protocol in the 1940s. The before and after pictures are witness to the "miracle at Carville." (From the collection of the National Hansen's Disease Museum, Carville, La.)

Hansen's disease and Covid 19 are clearly different diseases. One is a bacteria; the other a virus. HD is slow moving, rarely contagious or life threatening, and endemic in only limited areas; Covid spreads through the air rapidly, can be lethal, and is still at pandemic levels. However, the narratives of their treatment and cure have something significant in common: the dedication of scientists and medical professionals who have worked ceaselessly for successful treatments and cures; the bravery of many to subject themselves to trials and testing and finally the willingness of people to seek treatment (HD) or immunity (Covid 19).

Sr. Hilary Ross's dramatic photographs traced the improvement in patients who participated in Dr. Faget's drug protocol in the 1940s. The before and after pictures are witness to the "miracle at Carville." (From the collection of the National Hansen's Disease Museum, Carville, La.)

Source;

Fessler, Pam. Carville's Cure: Leprosy, Stigma, and the Fight for Justice. Liveright Publishers. New York: 2020.

World Leprosy Day: Celebrate It Everyday

by Claire Manes, Ph.D

As 2021 begins it is hard to realize that January of 2020 was medically “normal.” We were unaware of the novel corona virus, and we had no reason to believe that the year would take such a turn. In January of last year, I was honored to participate in some activities surrounding World Leprosy Day in Louisiana. Carville museum curator Elizabeth Schexnyder had organized educational programs across the state: librarians gathered patrons for book discussions, invited guests to learn about Hansen’s disease, posted exhibits. It was a full frontal assault to educate the public about a disease that many thought no longer existed. A common misconception was that it was a disease of the Bible that no longer occurred today.

I am certain that Elizabeth had plans to continue and expand the celebration in 2021. Sadly, we are still in the midst of masking, social distancing, and quarantining. World Leprosy Day will be different this year in many venues. Fortunately, its message is not silenced.

Proposed by philanthropist Raoul Follereau in 1954 the last Sunday in January was set aside to raise awareness of the misunderstood and feared disease, leprosy, preferably called Hansen’s disease. The day is still celebrated 67 years later. The Global Partnership for Zero Leprosy explains the day, “On World Leprosy Day we raise public awareness of leprosy, including the medical and social implications of the disease and the rights of persons affected. Social media campaigns, community parades, school programming, and cultural events are held around the world in the weeks leading up to World Leprosy Day.”

Faithful subscribers to The Star are already aware of the disease. They know that it is minimally contagious and curable. They also realize that it is still burdened with fear inducing myth. They recognize the pain felt by those still stigmatized by misunderstanding that surrounds the disease. Hansen’s disease is just that, a disease, but much more awareness is needed to remove the fear and ignorance surrounding it. World Leprosy Day reminds us of what we should do during the other 364 days of the year: work on ourselves and others to achieve acceptance of anyone who is marginalized and stigmatized. It is a day to remember the power that our knowledge can have to eradicate ignorance and achieve equity for all who suffer.

Greetings from HANDA in Guangzhou, China

by Dr. Michael Chen

On December 21, 2020, persons who have experienced Hansen’ disease and their families and members of HANDA celebrated the Winter Solstice. Thus is an important traditional festival in China with family gatherings and well wishes. This day is the shortest period of daylight and longest night of the year.

Unfortunately the year 2020 seemed like a gloomy and endless winter appearing to connect with a never ending winter of 2019.

In general the year of 2020 has been very difficult for everyone. The elderly in China’s rehabilitation villages, a high risk group coping with the stigma of Hansen’s disease and the uncertainties of the pandemic fueled virus, have had to live with strict management by the government as lockdown occurred. Fortunately, with their compliance with social distancing and support from others with HD no cases of the virus were reported.

As many made great efforts to raise funds and secure needed medical supplies for hard-to-access villages in Yunnan, the outcome became visible. In spite of a very challenging year, prevention plans succeeded in having a COVID free group of persons who have experienced HD.

All of us in HANDA look forward to a better and more economically stable 2021 and wish the same for all throughout the globe.

Leaning on the Hope for a Cure

by Tom Adams, R.Ph.

When faced with illness and disease, we look for a cure. We want relief, an end to suffering and death from a condition we hope to control. Most recently the advent and spread of COVID-19 initiated quests for cures. Early in the COVID-19 pandemic the anti-malarial hydroxychloroquine gained much attention for its touted success as a COVID-19 cure. Later in the pandemic hopes for a cure were placed on monoclonal antibodies. Now administration of COVID-19 vaccines is underway signaling cause for great hope that emphasis can shift from curing to preventing COVID-19.

Even before much was known about preventing diseases, for centuries there has always been hunger for curing diseases. Since ancient times, plant products have been a source to eliminate or alleviate human suffering from diseases. Some of the most noteworthy products from plants that remain useful to this day are digoxin from foxglove, quinine from the cinchona tree, opium from poppies and aspirin from the bark of the willow tree. Many herbal remedies used today are just as effective as they were long ago. Unlike times past, today we are able to chemically analyze plant products to determine their active ingredients. 1

Hansen's disease (HD) patients and those who have treated them share this same hope for a cure. Reviewing the quest for HD cures, in their 1964 publication, Cochrane and Davey wrote:

> A search of the literature during the past one hundred years or more reveals that almost every type of drug has been used in the attempt to bring about a cure of this disease. Very few remedies advocated during the past thirty or forty years are really new remedies. They have been tried by some workers at one time or another. These remedies include potassium iodide, arsenic, antimony, copper, sera, vaccines, and aniline dyes.2

More HD remedies are mentioned in a 1925 publication by Rogers and Muir to include thymol, strychnine, baths of various kinds, X-rays, radium, and electrical currents. Ultimately, it remained for chaulmoogra oil (a plant product) to become the mainstay of HD therapy for over a century. The authors recognized the product as "the one remedy which has been generally recognized for many years as of value in leprosy."3

fruit of Hydnocarpus tree

Chaulmoogra oil is expressed from the seeds of plants belonging to the family *Flacourtiaceae*. Their oil contains hydnocarpic and chaulmoogric acids representing the active ingredients against HD. The plants have both flowers and fruit and are the height of a bush or medium-sized tree. The genus *Hydnocarpus* includes the most valuable species in treating HD. Of these, species *H. kurzii (Takaktogenos kurzii)* was considered to provide genuine chaulmoogra oil, though oil extracted from *H. laurifolia (H. wightiana*) seeds was most commonly used since it was less costly than *Takaktogenos kurzii*. 4 Folklore credits a Burmese prince with discovering the use of the oil to cure HD. Upon contracting HD, he fled to the depths of the jungle to meditate on the evils of the world. A message from the gods told him to eat the many seeds of the fruit of a certain tree. He complied and his HD was cured.

Hydnocarpus flower on postage

In 1853 a British physician Frederick John Mouat working in Calcutta is credited with Western medicine's first use of chaulmoogra oil as a treatment for HD. Mouat reported healing of HD "ulcers" from external application of the oil and oral administration of seed pulp via capsule. Over time, oral administration of the oil was deemed more effective than topical applications. In 1901 Dr. Isadore Dyer began to orally administer drops of chaulmoogra oil for HD therapy of patients at the Louisiana Leper Home at Carville (so named until becoming the U.S. Marine Hospital No. 66 in 1921). Oral administration caused extreme nausea that became a deterrent for therapy. 5

In the final decade of the nineteenth century, trials of chaulmoogra oil injections via intramuscular or subcutaneous routes began and soon became widely accepted HD therapy. While injections did alleviate the nausea associated with oral administration, they were agonizingly painful and caused local reactions and fever. 6 As Stanley Stein (Carville patient and first editor of *The Star*) noted "Whether I was to take the oil externally, internally, or as someone once said eternally, was up to me. The oral doses were nauseously given out in the cafeteria at mealtime. The injections were administered in what was a distressingly public manner." Stein also noted "the after effects were sometimes frightful-painful, suppurating abscesses which the chaulmoogra oil would generate in the patient's backside." 7

By 1942 disagreements and skepticism over the efficacy of chaulmoogra oil therapy became common. As chaulmoogra oil was falling in favor, Dr. Guy Faget, Medical Director at Carville, introduced the sulfones. By 1947 sulfones had replaced chaulmoogra oil as treatment of choice for HD. Monotherapy with a sulfone gave way to multi-drug therapy to limit the chance of bacterial resistance to a single agent. Because of multi-drug therapy it can be said that HD can be cured. However, elimination of the disease awaits a vaccine.

With further advances since 1947 we can ask in reference to HD, when is a disease "cured" and was chaulmoogra oil a “cure”? Prior to today's scientific understanding, a cure depended on eradication of the causal agent of a disease. Despite numerous documented studies, physicians and researchers were unable to reach consensus about the healing power of chaulmoogra oil since it failed to eliminate *Mycobacterium leprae* from the body. The healing of lesions seen with chaulmoogra oil therapy did not equate to elimination and was often deemed a palliative response. Nonetheless, the oil provided hope for over a century as a cure for one of history's most dreaded diseases. 8 As long as infectious diseases remain unconquered, cures and ultimately eliminations will be hoped for and achieved in due season.

1. Chris Pitt, "Five old remedies that are still healing us today," https://www.bbc.com/news/health-34616695. Accessed 11 January 2021

2. R. G. Cochrane and T. Frank Davey, Leprosy in Theory and Practice, second edition (Bristol: John Wiley & Sons, 1964), p. 374.

3. L. Rogers and E. Muir, Leprosy (Bristol: John Wright & Sons, 1925), pp. 245-254.

4. 9 F Santos; L de SouzaI; A Siani,"Chaulmoogra oil as scientific knowledge: the construction of a treatment for leprosy" (Hist. cienc. saude-Manguinhos vol.15 no.1 Rio de Janeiro Jan./Mar. 2008), http://dx.doi.org/10.1590/S0104-59702008000100003 Accessed 11 January 2011

5. J. Parascandola, “Chaulmoogra Oil and the Treatment of Leprosy,” https://lhncbc.nlm.nih.gov/LHC-publications/PDF/pub2003048 pdf , pp. 2-4. Accessed 11 January 2021

6. ibid, p. 8

7. Stanley Stein (with Lawrence G. Blochman), Alone No Longer: The Story of a Man who Refused to Be One of the Living Dead (The Star 1974), pp. 38-39.

8 F Santos; L de SouzaI; A Siani,"Chaulmoogra oil as scientific knowledge: the construction of a treatment for leprosy" (Hist. cienc. saude-Manguinhos vol.15 no.1 Rio de Janeiro Jan./Mar. 2008), http://dx.doi.org/10.1590/S0104-59702008000100003 Accessed 11 January 2011.

Reflections on Stigma, HD and COVID-19

By Erika B. Ramirez

Erika and Mauro Ramirez from Houston, Texas recovered from COVID-19 and its accompanying stigma.

My dad, Jose Ramirez, defines stigma as "an act of labeling, rejection, or unexplained fear of something people don't understand." He formed this definition based on experiences and observations stemming from his journey with Hansen's disease (HD). Growing up, I often heard my dad speak out against stigma and its detrimental consequences. I generally understood the concepts and their importance, but, up until last year, I could not entirely relate. I never felt labeled, rejected or feared based on a medical diagnosis. While not comparable to my dad's experience, my husband and I had a small encounter with those sentiments when we contracted COVID-19.

My husband startled me at 3:00 a.m., "Do I have a fever?" From March through mid-August 2020, both of us had become increasingly vigilant as to any real or perceived physical ailment. So, he periodically asked me to touch his forehead. Every other time until then, he was fine. This time he wasn't. Fever caused him to curl up and shiver under the covers. His condition persisted into the next day, but he felt well enough to drive to a testing site. "It might be a sinus infection," he noted, as we both tried to evade the reality we suspected. That reality, however, imposed itself upon us the following morning when the doctor called, "Unfortunately, you have tested positive for COVID-19." I tested positive a few days later.

Fortunately, our symptoms did not require hospitalization or advanced medical care. Suffice it to say, however, an unpleasant experience clouded the next two weeks. I felt severe fatigue and recurring headaches. My husband's fever ran its course after twelve long days.

We more or less expected some of the events surrounding our COVID-19 experience. Like my dad's experience with HD, my husband and I felt love and support from family members and friends. But the reaction some people exhibited caught us by surprise.

Although many people reacted with concern when we disclosed our diagnosis, the most common initial question we encountered was, "Do you know how you got it?". This seemed like an unusual inquiry, especially ahead of, "How are you feeling?" Although not intended as insensitive, "How did you get it?" did not signal a great degree of empathy. In those interactions, we often became case-studies as though a friend, co-worker or relative was gathering anecdotal evidence to make analytical sense of COVID-19 for themselves rather than to sympathize with our experience.

Some people checked-in with us on a regular basis. Others, even people who we previously communicated with often, acknowledged our condition but never followed-up. Others, possibly jarred by actually knowing someone who had the virus, seemed to avoid the topic or us entirely. Others expressed mild degrees of discomfort, disappointment or, possibly, disgust. There was a thin veil between the words, "How did you get it?" and the implication, "What did you do to get it?"

We had worn masks and taken reasonable precautions. Even though we could not pinpoint how we contracted the virus, we blamed ourselves for getting sick. We felt ashamed and embarrassed. We must have done something wrong.

For weeks and weeks, messages to “flatten the curve” and “stop the spread” bombarded us and everyone else. Although it is entirely reasonable and expected for authorities to encourage precautions to combat a pandemic, it seemed that some people equated not getting the virus with the general notion of being a good or responsible person. Not getting sick signaled virtue while getting sick signaled, well, the opposite. A mindless, independent, unpredictable, uncontrollable, infinitely small virus floating up your nostril somehow indicated that you must have done something wrong. “How did you get it?” seemed to devolve into “What did you do to deserve it?”

For a few months after we recovered, my husband and I stopped disclosing that we had contracted COVID-19. Not only did we think we would be judged, but we anticipated the verdict: we were guilty for our illness.

What caused good people to react in an insensitive manner?

What caused us to feel that contracting a virus made us less than before?

I don’t know the precise answers to these questions. But they led me to reflect upon stigma, as defined by my dad. After some thought, one word seems to connect the dots: Fear. People were afraid of something they didn’t understand.

COVID-19 became all encompassing, yet, it remained shrouded in mystery. Unlike other conditions, doctors could not offer years of research or advice, as the virus both developed and dominated the globe within a few months. Further still, the virus seemed entirely unpredictable. Like a ghostly specter, it could manifest itself in whatever form it desired. For the asymptomatic, it felt like nothing at all. Or it could mix-and-match a seemingly endless list of ailments – cough, fever, diarrhea, body aches, shortness of breath, etc. And most tragic of all, it could bring death.

Although these circumstances call for a healthy degree of apprehension and caution, they also set the stage for the irrational and insidious fear that underlies stigma. “The unexplained fear of something people don’t understand.”

In this context, “How did you get it?” carried an inverse intent, “How can I not get it?” It seemed that many people were searching for an explanation and, at some level, a distinction. They hoped to learn that we engaged in risky behavior that they would never have entertained. Faced with the stark reality that someone within their own ambit had contracted the virus, they did what people tend to do when they sense a threat to their self-interest. They tried to make themselves feel safe by making others feel different.

After processing these emotions and reflecting on the stigma that my dad and his many HD brothers and sisters have endured over the centuries, the shame and embarrassment my husband and I felt melted away. We accounted for our actions in a reasonable manner and continue to take necessary and additional precautions. Like millions of people, my husband and I did not seek out the virus. Yet still, the virus found us. We hope that it does not find us or our loved ones again. But we will not sit and judge those who, through no fault of their own, are afflicted by illness.

We also began sharing our experience again, including the psychological impacts. Although we understand that some people approach our experience with underlying fear, I hope that they remember that we cannot let a virus sever the ties that bind us together as human beings. Maybe sharing our experience will help others or, at the least, serve as a small reminder that “How did you get it?” can easily be “How do we get through this?”

Sasakawa Leprosy Initiative Delivers Covid Relief Grants to Organizations of Persons Who Have Experienced Hansen’s disease

The Sasakawa Leprosy Initiative based in Tokyo, Japan is a strategic alliance between the Sasakawa Health Foundation, The Nippon Foundation, and the WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa. Yohei Sasakawa is not only the WHO Goodwill Ambassador but also the chairman of Nippon Foundation. The Nippon Foundation founded in 1963 and the Sasakawa Health Foundation founded in 1974 have been actively involved in achieving a world without leprosy through initiatives against the disease for over 45 years. This past year’s initiatives included a generous grant program of $340,000 (US) to 22 organizations.

In November 2020, true to their goals and cognizant of the new Covid-19 pandemic, the Initiative launched a grant program to support organizations of persons who have experienced Hansen’s disease while simultaneously providing their communities with essential support during the COVID-19 pandemic.

The program required that the applicants address the four pillars of the Leprosy Initiative grant program. These included: 1) responding directly to community needs such as the distribution of essential food, medicine and other supplies; 2) advocating with governments to ensure that the needs of those with HD are met; 3) disseminating information; and 4) enhancing the grantees capacity for self-direction and sustainability.

The organizations receiving grants were from 14 different countries and large country regions affiliated with NGOs including IDEA, MORHAN, PerMaTa, and NAPAL. The grant recipients were from Bangladash (2), Nepal (2), Niger (1), Mozambique (1), Senegal (1), India (2), Ethiopia (1), Kenya (1), Nigeria (2), Brazil (3), Sierra Leone (1), Indonesia (3), Philippines (1), and Tanzania (1).

In presenting the awards Yohei Sasakawa complimented the grant recipients for their “becoming increasingly vocal and active…in addressing needs in their communities….”

(The above is a summary of an article originally published in the website of Global Partnership for Zero Leprosy.)

The Price of Fear

by Claire Manes, Ph.D

Reading Erica Ramirez’s deeply sensitive reflections on her experience of stigma and fear inspired me to consider my own involvement with fear.

My grandfather Edmond G. Landry, who died thirteen years before I was born, had leprosy. It was not yet called Hansen’s Disease, and it was not yet curable. Instead, it was deeply feared by many including my grandmother, Claire Landry.

She guarded against the disease with her amulets: rubbing alcohol and silence. In her mind,the rubbing alcohol would protect her two children and herself from the bacillus, and the silence would guard against the lies and prejudice surrounding the disease in the 1920s.

Armed with today’s knowledge we might be inclined to judge my grandmother and others like her harshly. However, we need to understand her in her times. In October of 1924 at the age of 26 she was left alone to care for and protect the couple’s five year old daughter and three year old son. Claire’s brother-in-law had died in Carville only eight months earlier and her sister-in-law already manifested symptoms of the disease. Ultimately HD claimed all five of the Landry siblings. No one in any succeeding generations has contracted Hansen’s disease, but we have all been shaped by my grandmother’s fear. Rubbing alcohol remained a staple in her cabinet and silence sealed our lips.

It was only years after my grandmother’s death that we began to talk about my grandfather. The silence that we absorbed had separated us from the loneliness and pain that he endured. It deprived us of stories about him and memories that he and our grandmother must have shared. It deprived us of our grandfather.

Fear does such things.

…And know that someone in the world has been taken care of

by Mary O'Friel

"When I see and hear you, I become proud that I can belong to this team. I hear of the activities you have organized in your countries, and know that someone in the world has been taken care of."

Lucrecia Vasquez, Felehansen, Colombia,
IDEA hosted Gathering

The International Association for Integration, Dignity and Economic Advancement, IDEA, continued hosting semi-monthly Gatherings via Zoom, for persons around the world who have experienced Hansen's disease. Begun at the end of March as a response to the COVID-19 global pandemic, the Gatherings have continued to serve as a way for people to connect with and support each other, sharing personal experiences and providing updates on the situation in their local and national communities. The Gatherings truly fulfill IDEA's mission to "network persons around the world who have experienced Hansen's disease, to empower each other, to ensure human rights and to promote inclusion."

Gatherings have also included presentations and discussions with related experts, which have had the unplanned outcome of capacity building. Participants play a central role in organizing these sessions, identifying topics, planning presentations, and moderating discussions. IDEA provides administrative support including liaising with guest presenters, preparing announcements, facilitating interpretation, identifying moderators, supporting technology, and continuously identifying new participants.

Discussions have been held with experts including Zoica Bakirtzief da Silva Pereira, Jayashree Kunju, Suresh Dhondge and Valsa Augustine (ILEP stigma guidelines through peer-to-peer learning); Alice Cruz (human rights); Julias Eaton, MD (mental wellbeing); Claudio Salgado, MD (medical issues); and Liesbeth Mieras, MD (new prophylaxis). Presentations are recorded and shared to reach people who are not able to attend.

Beyond the initial intent of the Gatherings, these discussions foster relationships and increase networking among experts by experience and physicians, researchers, and other experts in the field, creating a forum for equal participation and knowledge exchange.

As a result of the positive feedback from participants, IDEA will continue the Gatherings into 2021, and look towards formalizing this platform, to join people from around the globe to learn from each other and strengthen advocacy.

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RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

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

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

FACTS ABOUT HANSEN'S DISEASE

What is HD?

Hansen's disease, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr. Gerhard Amauer Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without difficulty and counteract most of the fears generated by the folklore surrounding this disease.

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

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

Where is HD Found?

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

NHDP SERVICES Website: www.hrsa.gov/hansens