

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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1921—2021
100 Years of Advocacy and Research

Photo by James L. Krahenbuhl, PhD, former Director, NHDP and Chief LRB

CONTENTS

January 2021-June 2021 Vol. 64-29

Celebrating 90 Years of The Star
by Claire Manes, Ph.D......3

Current State of NHDP and Patient Care
by Kevin Tracey NHDP Director7

Penikese Exhibit.....8

History and Contributions of the Laboratory
Research Branch.....9

In Memorium Dr. P. K. Gopal 1940-2021.....12

Hansen's Disease Clinics.....15

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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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Celebrating 90 Years of The STAR

by Claire Manes

Eight Editors from Two Continents with One Universal Message

Stanley Stein The Founder

Gossip, scores for softball and golf, Sunday dinner menus, and previews of coming attractions appeared in print for the first time ninety years ago on May 16, 1931. On that day The 66 STAR was born. The legal sized two column mimeographed paper featured Carville news by Carville patients. Cartoons, jokes, and articles by the residents became The Sixty-Six STAR in a nod to Stanley Stein's hometown newspaper and the United States Public Health Hospital #66. For the first time patients had a paper telling their stories in their own words. Stein's brainchild birthed less than three months after his arrival in Carville gave an identity and voice to men, women, and children who had been voiceless even in the confines of the hospital. The patients themselves made, collected, and wrote the news then typed, printed, and distributed the in-house newspaper.

As Carville residents observed their names and activities in print, they realized their value, power, and voice. Over a three-year period, the paper made inroads into the patients' efforts to achieve agency for their lives. By 1934 emboldened by The Sixty-Six STAR's success and Stein's desire to change false attitudes toward leprosy, Stanley Stein and editorial writer/researcher Eugene Williams initiated an in-print conversation with the hospital's Catholic chaplain addressing the Catholic Church's role in fostering erroneous information about the disease especially during the Middle Ages. Their efforts were not well received by the volunteer patient staff, many of whom were Catholic. The staff quit or simply failed to show up for work. Stanley Stein's dream died, and he was left drained, exhausted, and depressed, but not permanently deterred.

In 1941 with the help of the Forty and Eight Veterans' organization which had adopted The STAR as their national project, Stein renewed his plan to radiate the truth about Hansen's disease. What had started as an in-house publication in 1931 became an international publication and a forum about Hansen's disease. The staff, volunteer patients who were later paid a minimum wage for their work, gathered and wrote articles, set them in type, took and developed photos and created art for the covers. The new STAR expanded its outreach internationally. Within two years a new printer acquired during war time enhanced the journal's capacity to produce a quality publication. The STAR featured local news, summaries of advocacy efforts in endemic countries, and updates on all aspects of Hansen's disease research. For those who experienced HD around the world, the news of other brothers and sisters with similar struggles brought joy to their lives. In the 1940s part of that news was the "Miracle at Carville," the first successful effort at treating the disease. Just as the bacillus had expanded around the world, the news about the drug that killed the bacillus spread. Many with HD in Japan, India, China, Nepal and other endemic countries received the hopeful news through interpreters who read every word in The STAR to those desperately searching for hope.

Stanley Stein, a Texan by birth, led the Star for more than 20 years with passion and conviction. He became an unstoppable force determined to eradicate the use of the word leprosy and the even more painful "L" word. He challenged the Catholic Church, Hollywood, print, radio and later television media anytime he felt they misrepresented the truth of the disease that had isolated and ostracized so many. He showed the world that a man blind and segregated from society because of a disease could change the world with persistence and determination. Each of the succeeding editors: Louis Boudreaux, Ray Elwood, Emanuel Faria, Willie Kikuchi, Abel Aparicio, Simeon Peterson, and José Ramirez accepted Stein's mantle and brought their personal experiences and passion to the position.

Louis Boudreaux Filled Big Shoes

Mr. Stein maintained The STAR from 1941-1964 when at his behest Louis Boudreaux became editor. Some of the later editors had international roots, but Mr. Boudreaux hailed from Donaldsonville, La., less than 30 miles from Carville. Like Mr. Stein, Mr. Boudreaux was blinded by HD but undeterred in his mission to maintain The STAR. He had worked with Stein on



Stanley Stein, the STAR founder. His cluttered desk belies a clear mind.



Ray Elwood, (left). Louis Boudreaux (second from left) and Emanuel Faria (far right) celebrate the paper back edition of Stanley Stein's book *Alone No Longer*.

the publication and was "ready, willing and able" to carry the torch. As editor he created the first editorial board to help with the task of publishing the monthly international journal, a model that continues today. Under his leadership The STAR grew from 24,000 subscriptions to 86,000 in 1986, with subscribers in the United States and 150 foreign countries. (Elwood, Louis) José Ramirez recalls Mr. Boudreaux as always having a favorable attitude about life. He walked throughout the facility's enclosed walk ways tapping his cane anticipating anyone walking or riding a bicycle past him. When riders came too close to his cane, he would jokingly threaten to switch places with them.

Ray Elwood Followed the Pioneers

Ray Elwood took up the pen in 1985 when Louis Boudreaux's health failed. Ray had arrived in Carville in the 1940s and represented a new generation of HD patients, the post-miracle generation. He recalled his early experience working on The STAR, taking dictation from Stanley Stein. "I knew how to type but I had never taken dictation before. It was an experience that I have never forgotten. The man was using words that I had never heard before.

After leaving his office I spent half of the day looking up the words in the dictionary." As the editor, Ray faced challenging financial issues. The STAR had a circulation of 92,000 in 132 countries including Russia and China, but subscriptions were still \$1.00 per year. Under Ray's stewardship the price was raised to \$2.00 annually. It was a necessary decision, but one that Ray called one of the most difficult decisions made by him and the board. He took pride in following Stein and Boudreaux whom he called the "real pioneers of The STAR." ("The Elwood Era.")

Before he was ever The STAR editor, Ray and Willie Kikuchi, another editor, were members of the Point Clair Indians, the hospital's racially and culturally integrated softball team that took the River League championship against powerful all-white teams in the area. The Indians played all of their games at "home" as the patients were not allowed to travel outside of the Carville gates. Segregated by HD, they were the only racially integrated team with Asian, Black, Hispanic, and White players. During this period of overt segregation in Louisiana, the all-white teams, bringing their own bats and balls and their fans, would appear at the home of the Indians to play softball. White fans of the opposing teams sat in separate stands near the diverse fans of the Carville team. For an afternoon at least bats, balls, and young men hitting for championships breached the barriers of segregation and stigma.

Emanuel Faria Contributed to the Pool of Good

When Ray Elwood resigned as the editor of the STAR, Emanuel Faria became the journal's first internationally born editor. Stein, Boudreaux, and Elwood were from Texas, Louisiana, and Florida, but Emanuel Faria was a native of British Guiana (later Guyana in 1966). He arrived in Carville in 1968, two years after his country achieved independence. He came seeking medical assistance and protection from the political unrest and persecution he had endured at home. He knew The STAR from his years in the hospital in his home country and brought with him his deep appreciation of the publication and his admiration for Stanley Stein. Ramirez recalled Mr. Faria as a man with many physical disabilities and a sharp mind. Despite his challenges, Mr. Faria maintained a belief in the necessity to do good. "My philosophy of life is that we all have to contribute to the pool of good.... We cannot expect others to contribute while we just go and draw from it and don't put anything into it. When I was given the opportunity to work at The STAR, I felt I was contributing something." That drive to contribute to the pool of good also led Emanuel to serve as a Board member of the American Leprosy Mission along with Dr. Trautman, the Medical Director of Carville.



Emanuel Faria developed his own unique typing strategy.

Emanuel noted that had his life been HD free, he might have gone into medicine. HD changed his vocation but spurred him to focus on medical issues surrounding the disease. Emanuel added more medical articles to the STAR bringing his own passions to the publication. (Thomassie)

Elizabeth Schexnyder, Curator of the National Hansen's Disease Museum, shared her memories of Emanuel. "When I

began as museum curator in the early 2000s, I learned, while introducing myself to Emanuel, that we shared a common love of classical Greek and Roman history. I enjoyed getting to know him, slowly, as we shared lunchtime conversations in the Carville cafeteria. I remember being stumped by his accent—a rolling and lyrical drawl that I couldn’t place. I could tell he was a shy man, but very intelligent. He told me pieces from his early story as a young man in a leprosy settlement in South America. His gratitude at finding himself at Carville all these years later was still palpable. Emanuel was also fiercely independent, and I knew we were becoming friends when he asked for my help to order esoteric history books on the Internet. I easily keyed in the information on his keyboard, while he used a modified pencil with a thick rubber eraser to type—his hands had become clawed over the decades of insensitivity. Regardless, he remained engaged and inquisitive until the end, good traits for a good editor to have. I wish I could have known him longer.”

Willie Kikuchi Served the HD Cause Beyond Carville

Willie Kikuchi had been discharged from Carville and lived near New Orleans, but would drive to Carville to assist with the magazine during Emanuel Faria’s editorship when the publication was transitioning to an electronic platform. When Emanuel retired, Willie became editor. Like Emanuel Faria, Willie Kikuchi had experienced political persecution even before the stigma of HD. A first generation Japanese American, Willie and his family were interred in a concentration camp in Nevada at the start of World War II. In the camp Willie, his mother, and siblings were diagnosed with HD and interred again, this time in Carville. His early life experiences left him determined to treat others fairly. “Because of what I have endured, I try to instill in my family that discrimination for any reason is wrong for it breeds hate. It can and will consume you...I admire people for who they are, for what they do....” Willie Kikuchi lived the life he admired in others, cherishing his family above all and working on behalf of the truth about Hansen’s disease not only as a Carville resident and editor of the STAR but also in his service to IDEA. (Law) Early in his time at Carville he also proved what he could do on the diamond; he and Ray Elwood were among the young men at Carville who won the River League Softball championship.



Will with his family: (Left to Right) Nikki, Margaret, Cliff and Anna. (Cliff Kikuchi Facebook post)

Abel Aparicio Found Love at The STAR



Abel Aparicio loved the STAR even before he found love with Yolanda.

Another international patient and a refugee from Communism, Abel Aparicio succeeded Kikuchi as STAR editor in 2006. He and several other Cubans who fled Castro’s regime in 1970 were then sent to Carville for treatment of HD. These Cuban residents worked tirelessly operating the laundry for both patients and staff. Mr. Aparicio served on STAR staff from his earliest days and enjoyed telling people how much he loved his job. He also found love in the STAR office, marrying Yolanda on July 17, 1976. (People) Abel was the first Spanish speaking editor and brought his own perspective to the paper. In a STAR article entitled “The Show Must Go On” Mr. Aparicio was remembered as “having a unique perspective of Carville and its residents... [his] gentle demeanor allowed him to capture the essence of life at Carville.”

Simeon “Mr. Pete” Peterson Ambassador and Historian

Willie Kikuchi and Abel Aparicio were challenged with an aging and diminishing staff and a printer that was no longer state of the art. The 40 & 8, faithful partners with the paper, assumed the publishing responsibilities, moving them to their central office at about the time Mr. Simeon Peterson became the editor. Mr. Peterson aka “Mr. Pete,” “Doctor Pete,” “Ambassador Pete,” and “Historian Pete” was the last editor to spend most of his life at Carville. He arrived in Carville at age twenty-three from the United States Virgin Islands and always considered the place his home. Like Emanuel Faria, Mr. Pe-



Mr. Pete, long time Carville resident, the STAR editor, and ambassador extraordinaire

terson had had a connection to The STAR during his hospitalization in the Virgin Islands. Fidelity to his duties to Carville and to his fellow patients was his hallmark. He delivered patients and messages to labs, therapy, and meals. He operated the elevator for a time and earned his title Dr. Pete for delivering another form of “medicine,” cold beer and soft drinks, to patients at Carville softball games. When most of the last patients had moved to Baton Rouge, he became historian, ambassador, and tour guide for the museum riding his three-wheel bicycle and sharing the hospital’s history and his personal story of HD with visitors. In this ambassadorial position he humanized individuals who had long been stigmatized. His service to The STAR added a dimension of history to the paper insuring that its past would not be forgotten.

José Ramirez Expanded the Focus of The STAR

Following Mr. Peterson’s editorship Jose Ramirez, Jr. became the editor. He had served on the Editorial Board for several editors; in 2009 he accepted the role of Managing Editor and assumed the editorship in 2018 following the death of Simeon Peterson. His term as editor has been influenced by his long connection with Carville. Jose arrived in Carville from his home in Laredo, Texas in 1968 a month after Stanley Stein’s death. He was one of the youngest residents in an aging community, a lonely position that gave him a different involvement with the residents. José served in positions that had long been established within the Carville population: in the canteen, as an instructor at the Carville school, and as a tour guide at the hospital. He was also a young voice at the Patient’s Federation and as a member of the Patients’ Lions Club. José remembers that with the advocacy of the hospital social worker and medical director, he became the first Carville patient to be admitted as a student at Louisiana State University. The university, 20 miles from Carville, had a policy that barred anyone with HD from working at or attending the school. At LSU José was a one-man spokesperson for the truth about HD, but he also felt the stigma experienced by Black students on campus. Medication that treated his HD also darkened his complexion and he felt the pain of the “N” word, hurled at him by irate segregationists including the Grand Dragon of the Ku Klux Klan, also a student on the LSU campus.



Unlike some of the earlier editors and many patients at Carville, José spent most of his adult life outside of the hospital, but he has always carried a deep love and compassion for his brothers and sisters with HD. The freedom to live, travel, marry, and raise a family outside of Carville has given him a worldwide platform from which to radiate the truth about Hansen’s disease. As editor he has emphasized the work of multiple international groups and organizations that advocate for respect and autonomy for themselves as people with HD. He added to the purpose of The STAR a third aim: to “Foster self-empowerment of those who have experienced HD.” He has also included second and third generation family members of HD persons to The STAR editorial board thus bringing another perspective to the paper. José has followed in the footsteps of the seven editors who preceded him and has, like them, put his own stamp on his position. In the past year Ramirez and The STAR have highlighted issues surrounding the COVID pandemic recognizing that fear and stigma find many different targets and that empathy and truth are the antidotes to prejudice.

It is tempting but futile to wonder what these eight men would have achieved had they not been confined in Carville. However, it is clear that their passion for the truth about Hansen’s disease and their advocacy against prejudice have reached farther than any of their individual lives would have stretched.

As this issue of The STAR was going to press, we learned of the death of Dr. John Trautman at the age of 94. He was a well-beloved administrator in Carville. We acknowledge his death, offer our condolences to his family, and promise the tribute he deserves in the next issue of The STAR.

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Kevin Tracey NHDP Director Updates the Current State of NHDP and Patient Care

Recently the STAR editors interviewed Kevin Tracy, MS, RN Director of the National Hansen's Disease Program in Baton Rouge, La. The interview follows.

The STAR: As an introduction to our readers, please share your personal and professional background.

KT: I am educated as a registered nurse (BSN) and I hold a master's degree in administration (MSA). I have worked in many facets of nursing to include ICU, PACU, OR and Case Management. I have held several leadership positions in both the U.S. Army and U.S. Public Health Service. I retired from USPHS in 2020.

The STAR: Stanley Stein, who started the STAR, was a great advocate for inclusive services and against negative labeling. What is your view on Hansen's disease related to services and the battle against stigma in the United States for the rest of the year and into 2022?

KT: I personally am an advocate of education and presenting the truth, and I believe that education is the best way to combat stigma. NHDP employs a full-time social worker with research interests in the social determinants of health and stigma and a full-time nurse consultant that assists with case management and patient education. NHDP also recently hired a full-time outreach and education coordinator. This role is tasked with increasing our education offerings to the provider community and public. All of these roles will assist in combatting stigma for present and future HD patients.

The STAR: My inpatient number was 2855 (in 1968). What was the last number assigned to someone admitted to Carville? How many of those admitted to Carville are still alive?

KT: The last inpatient number assigned was 4533. NHDP currently has one remaining long-term patient, who is cared for locally, and eight (8) patients that receive a monetary stipend from the program.

The STAR: Is our research department collaborating with other global programs and what is the most important issue?

KT: Our Laboratory Research Branch continues to collaborate on a global scale with other leprosy researchers (Leprosy Research Initiative and American Leprosy Mission, etc.) though it is difficult to name the "most important issue." Through an NIH grant, NHDP maintains the only known supply of reagent-grade leprosy bacillus available to researchers worldwide. On a regular basis, NHDP successfully competes for other research grants to test new treatments.

The STAR: How many HD clinics are funded by the NHDP?

KT: NHDP funds eleven contracted ambulatory care programs.

The STAR: How many HD patients do you serve annually?

KT: NHDP currently serves approximately 1200 active patients through the Center of Excellence in Baton Rouge and the eleven contracted programs.

The STAR: How many newly diagnosed cases does the United States have annually?

KT: The estimated number is 150-200 cases per year –unchanged for several years.

The STAR: What is the breakdown by age, sex and nationality/ethnicity?

KT: That specific information is not available, but statistics show HD affects men more than women (~ 2:1) and the mean age of women that contract HD is lower than men (~40:45). As you may know, the U.S. has a large population of Pacific Islanders with HD.

The STAR: In 1999, President Clinton signed an Executive Order granting a lifetime stipend to those who agreed to leave Carville voluntarily and life-long care for patients that chose to stay. How many were in each group and how many are still alive?

KT: The original number in each group is not available in our office, but 8 patients who chose to leave voluntarily are still alive.

The STAR: *What is the age of the youngest and the oldest?*

KT: No exact figures are available, but most of the remaining Carville patients are in their 80s and 90s.

The STAR: *How does the NHDP promote the World Leprosy Day?*

KT: The NHDP provided regional outreach events at Baton Rouge area libraries in 2020. Due to COVID restrictions and the mass number of commissioned corps deployments, we were unable to provide any outreach for WLD 2021. The main goal of the new outreach and education coordinator is to increase these offerings not just for WLD but year-round.

The STAR: *Does the NHDP have a system in place to promptly correct electronic or verbal myths about HD?*

KT: NHDP continues to educate to correct misinformation. One of the primary tools to prevent misinformation is the NHDP website, which contains up-to-date, accurate information on the disease and we collaborate with our headquarters in Rockville, MD on using social media and other avenues to correct misinformation.

The STAR: *How has availability of the NHDP services been impacted during the COVID restrictions?*

KT: No services were impacted. The Baton Rouge clinic and contracted clinics continued to see patients as needed during the pandemic. NHDP continues to coordinate services as close as possible to the patient's residence. We have also ramped up our telehealth services during COVID.

The STAR: *When do you expect to return to "normal"?*

KT: We have no way to predict what course the COVID-19 pandemic may take, and when additional changes may occur. However, as previously noted, the NHDP is able to operate effectively in spite of the challenges we are currently experiencing

The STAR: *The NHDP Clinic in Baton Rouge has recently moved to a new location. Has this changed any services offered?*

KT: No, if anything it has increased the services we can offer. Our new state-of-the-art conference center will allow us to increase both our in-person and remote education offerings.

The STAR: *Is the NHDP still able to house and care for patients who need referral for specialized care?*

KT: Yes, we have five (5) domiciliary rooms in the new building in Baton Rouge.

The STAR: *Would they still stay at Carville?*

KT: No, patients will no longer stay at Carville—a benefit since short-stay patients are no longer subjected to the 1.5-hour daily roundtrip commute. Additionally, when short-stay patients are done with appointments for the day, they can return to their rooms and not have to sit around waiting for transport back to Carville.

The STAR: *We have heard that in a reorganization within HRSA, the NHDP has been moved to a new bureau. Can you share more information about this change? Will this affect NHDP operations? Has the budget been reduced?*

KT: To date, no changes have been made that affect the NHDP. The NHDP budget has remained at the same level for the last three years.

Penikese Exhibit

From November, 1905 to March, 1921 Massachusetts administered a hospital for people with leprosy on the barren 74-acre island of Penikese in Buzzards Bay, midway between Martha's Vineyard and New Bedford. During those 16 years the hospital cared for 36 patients at great expense. For them the hospital was also a prison. This October the Public Health Museum in Tewksbury, Massachusetts will commemorate the centennial of Penikese closing with a six-month exhibit. The exhibit will kick off online with a panel of speakers, and will include virtual components viewable anywhere in the world. For details please visit www.publichealthmuseum.org.

History and Contributions of the Laboratory Research Branch

David M. Scollard MD, PhD¹ and Richard W. Truman PhD²
1= Director (ret) 2= Chief (ret), Laboratory Research Branch
HHS/HRSA/HSB/National Hansen's Disease Program

In 1967, for a special edition of *The Star* (27:1) focused entirely on HD research, Dr. Merlin Brubaker, the then Medical Officer in Charge at Carville, responded to a question about the need for research on Hansen's Disease. He replied that research "is necessary in order to provide better [diagnosis], treatment ... and a greater understanding of the disease and its processes... and how they impact people affected by HD". Research has always been an integral part of the mission of the National Hansen's Disease Program. From the time of its founding in 1894 by the State of Louisiana, local academic leaders sought to mainstream care and treatment of HD with links to local Universities and Medical Schools. Over the years many strong collaborations evolved.

Though particularly well known for its clinical contributions in the development of new drugs and effective therapies for managing HD and its complications, the Program also has a long history of laboratory-based investigations. Even as early as 1910 C.W. Duval and Maurice Couret were traveling up the Mississippi river from Tulane University in New Orleans to Carville to collect lesion materials which they used in attempts to propagate *Mycobacterium leprae in vitro*, as well as to transfer the infection to a number of different animal hosts including mice, Rhesus Macacus monkeys, and a wide variety of hosts with cool body temperatures such as gold-fish and reptiles.

Initially, laboratory investigations were coordinated through the Laboratory Branch, which also oversaw operations of the clinical laboratory, pharmacy and pathology services. With Charles Shepard's landmark discovery in 1962 that *M. leprae* could be propagated in the foot pads of mice, however, a wide range of new investigations could be pursued especially with regard to the development of new drugs, and for better understanding immunity and resistance in HD. Large numbers of experimental animals were required, new animal quarters were built, and the ever-increasing complexity of studies also required new and additional expertise.

Dr. Waldemar Kirchheimer, a medical doctor with expertise in Microbiology was appointed to oversee the Microbiology Research Services in 1962, and he was soon joined by Dr. Kochukunju Prabakaran to pursue biochemical investigations. In 1967 Dr. Kirchheimer began collaborating with Dr. Eleanor Storrs of the nearby Gulf South Research Institute. Together they showed that nine-banded armadillos were susceptible to experimental infection with *M. leprae*, and the bountiful numbers of bacilli they made available for investigation became a boom to HD research worldwide. After becoming Director of the Program in 1967, Dr. John R. Trautman established the Laboratory Research Branch (LRB) under Dr. Kirchheimer's direction, and markedly expanded the research personnel with expertise to include lead investigators in Microbiology, Biochemistry, Pharmacology, Immunology and later Molecular Biology and Pathology along with additional junior and support scientists in these disciplines.

The various research projects at the LRB over the years have pursued a variety of basic scientific aspects of HD, but they have always been related to important issues in the clinical diagnosis and management of this disease. Major contributions in the **diagnosis** of HD have emerged from studies related to the genome of *M. leprae*. LRB has been a leading laboratory in the application of the polymerase chain reaction (PCR) to detect *M. leprae* DNA in tissues. This has become increasingly important as a method to confirm the diagnosis, and to distinguish between *M. leprae* and other mycobacteria in the skin, because using standard staining methods all mycobacteria look the same. Continued advances in PCR technology hold promise for the use of this method for earlier diagnosis, also.

Another major advance has been the use of PCR to distinguish between different 'strains' – more accurately, 'genotypes' -- of *M. leprae*. This is particularly important and valuable in understanding the transmission of this germ (discussed below). LRB is one of a number of laboratories around the world that continues to develop better, faster, cheaper techniques to perform genotyping of *M. leprae*.

More advanced molecular techniques, especially those related to the study of RNA, have given researchers the ability to study basic aspects of the function of *M. leprae*. Among other things, these studies have begun to explain why *M. leprae* is

uncultivable, and can only live inside another cell such as in humans or armadillos. Certain types of RNA are only seen in living bacilli, and this offers new possibilities to determine whether a drug has killed them.

The first effective **treatment** of HD began at Carville in the 1940's, with the discovery of the benefit of dapsons. Since that time, the LRB has continued to search for additional, more effective drugs. The fact that *M. leprae* cannot be cultivated in the laboratory has always been a major obstacle in the development and testing of new drugs to kill it. For decades the LRB has tested potential new drugs using by inoculation and growth of *M. leprae* in mouse footpads, treating the infected animals with the drug of interest. This is the 'gold standard' method but it is very slow and expensive, requiring dozens of mice and a year or more to provide an answer. Additional methods developed at LRB enable researchers to monitor the respiration of *M. leprae* – actually measuring its metabolism, as well as methods using different staining chemicals to identify living vs dead bacilli under the microscope. These tests require large numbers of bacilli and can only be done in such a specialized laboratory, but they have provided the LRB with unique capability to screen candidate drugs as a pre-requisite for human studies.

Now the LRB has developed a method to measure the viability of *M. leprae* directly from a skin biopsy, using a combination of the molecular techniques mentioned above. This new molecular viability assay (MVA) can therefore determine whether or not a drug (or combination of drugs) has successfully killed *M. leprae* in a particular patient. Unlike the other tests, the MVA is 'field-friendly' – it requires a much smaller number of bacilli, and the biopsy specimen can be taken at the patient's clinic or health center and sent to the laboratory without special requirements (such as dry ice). This means that, for the first time, doctors have a test to determine the effect of a treatment for HD that is comparable, in clinical practice, to the standard culture techniques used to determine the killing of other bacteria after treatment.

Drug resistance is another important consideration in the treatment of HD. The LRB is a WHO collaborating center in a global effort to monitor the presence of *M. leprae* that are resistant to the major drugs used to treat HD. Initially, this was done using the mouse footpad method. This provided scientifically sound results but, as noted earlier, it is very slow and expensive. Studies at the LRB and other research institutes around the world have identified mutations in *M. leprae* DNA that are associated with resistance to each of the main anti-*M. leprae* drugs. Tests to detect these mutations enable a much faster and less expensive means to identify drug resistance when it occurs, and to guide physicians to modify the drug regimen for patients as needed.

LRB is now able to combine all of these molecular capabilities, so that *M. leprae* DNA from patients can be amplified by PCR to confirm the diagnosis, assessed for mutations associated with drug resistance, and genotyped for epidemiological studies, and may soon also be tested for viability.

Nerve injury is the major medical consequence of HD, and is the result of the unique ability of *M. leprae* to infect peripheral nerves. This infection of nerves is the basis for most of the physical disabilities in HD. Impairment of nerve function was well documented in HD over 100 years ago -- even before Hansen discovered *M. leprae*. However, it is very difficult to study the specific mechanisms by which *M. leprae* infects and injures nerves because to do so we would need to examine the nerves directly, but we cannot biopsy of the most affected nerves because this would further disable a patient. So, to study nerve infection in HD an animal model is needed. In the late 1990's scientists at LRB demonstrated that the nerve involvement of experimentally infected armadillos offers a model that closely resembles what happens in human nerves in HD. Nerve conduction tests used for humans can, with modifications, be used to detect clinical abnormalities of nerve function in armadillos. A variety of laboratory techniques, including new molecular methods, have also been applied to study immunological and inflammatory activities in these infected nerves.

Basic studies of animal models sometimes have unexpected benefits. Such was the case one afternoon a few years ago, during safety trials of a candidate HD vaccine in armadillos. Poring over many pages of data, to the scientists' surprise they observed that among experimentally infected animals, those that received the vaccine had delayed -- and less -- nerve injury than animals that were not vaccinated. The candidate vaccine appeared to reduce nerve injury in infected armadillos! As a result, planned human trials of the vaccine will monitor nerve function very carefully to see if the vaccine has this same benefit in human patients. The mechanisms responsible for this are still under investigation.

Basic issues related to the **epidemiology** of HD remain among the most elusive questions about this disease, especially issues related to the transmission of *M. leprae*. Addressing this, two of the signature capabilities of the LRB have come together: molecular methods to study *M. leprae* DNA, and field studies of the armadillo. Using PCR and genotyping methods, LRB investigators in 2006 published a landmark paper in the New England Journal of Medicine demonstrating that humans and armadillos in the southeastern United States share the same genotypes ('strains') of *M. leprae*. Preliminary findings from

other studies suggest that this is also true in Central and South America.

This has profound implications for the epidemiology and control of HD, telling us that human-human transmission is not the only means of spreading *M. leprae*. As a result, at least in the Americas, public health initiatives to control this infection must also take into account the fact that armadillos may be an important source of new cases of HD in people. At a recent international HD research meeting, comments by Dr. Erwin Cooreman, Team Leader of the WHO Global Leprosy Program, acknowledged the importance of this work and of the armadillo as an environmental reservoir of *M. leprae*.

Gradually, as if emerging from the mist of history, a picture is developing of the distribution of the different *M. leprae* strains around the world. This offers insights into the transmission of *M. leprae* in past decades. But as the technology improves, it is likely that this will enable real-time assessment of the strain distribution of *M. leprae* within smaller, localized regions. This is potentially very valuable in advising programs on how to direct resources to deal with ongoing transmission and surveillance for new cases.

Only a handful of laboratories remain in the world that have substantial capabilities for laboratory-based HD research, and none of them have both the breadth and depth comparable to the LRB. The array of tests for *M. leprae* viability, molecular studies, and both armadillo and mouse footpad models is unique to the LRB. An important spin-off of this is the maintenance at the LRB of well documented, high viability *M. leprae* strains -- even labeled with fluorescent markers if requested! In addition, the LRB is the only laboratory globally to isolate and carry in culture the newly recognized organism *M. lepromatosis* which also is associated with HD. These supplies create an important infrastructure of research reagents for the scientific community, and are provided to other laboratories around the world.

From this brief summary of accomplishments of the LRB, and their relevance to the clinical diagnosis and management of HD, it is evident that research such as this is essential to future progress in controlling and eliminating HD. It has taken decades of dedicated effort to build this unique resource. In that same special 1967 edition of *The Star* mentioned previously it was estimated that there were fewer than 16 full-time U.S. HD researchers in 1967. Clearly, there are fewer than half that number today.

Research is not a luxury or a frill -- it is a basic investment and foundation for the future. Because the resources needed to conduct such research are beyond the financial capabilities of many of the remaining endemic areas of the world, and cases anywhere potentially impact the United States as well, the LRB is a unique resource of national and international value. It is a rare gem!

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In Memorium Dr. P. K. Gopal 1940-2021

In 2005, Dr. P.K. Gopal visited the site of the home of Mahatma Gandhi in Johannesburg, South Africa, something he would never have dreamed possible when he first developed signs of leprosy some 48 years earlier while studying in high school. Following the African Regional Leprosy Congress in Johannesburg that year, he participated in an international conference, co-sponsored by IDEA, on Robben Island, where the prison that Nelson Mandela was housed in was built on top of the graves of people who had leprosy.

The world of leprosy has changed significantly since the days of Gandhi and the days when the history of those who had this disease was virtually erased from the memory of Robben Island and other places. It is not only the sulfones and MDT that have changed the world of leprosy, but the determination and wisdom of those individuals who have turned a diagnosis of leprosy into a personal challenge, and ultimately a personal victory.

One of those individuals was Dr. P.K. Gopal, who passed away on March 18, 2021. Dr. Gopal lived his life with grace, wisdom and dignity. He turned his personal challenges into a vehicle through which he worked to improve the lives of people who have had leprosy both in India and throughout the world. Although Dr. Gopal represented individuals affected by leprosy around the world as IDEA's President for International Relations from 1994 until shortly before he passed away, he also refused to let himself be defined by the disease. First and foremost, he was a social worker.

Dr. Gopal received his Master's Degree in Social work in 1972. That same year he started the first Department of Social Welfare and Rehabilitation in a leprosy hospital in India (Kumbakonam) and became the first professionally qualified social worker to work in the field of leprosy in India. In 1984, he presented a paper on rehabilitation at the XII International Leprosy Congress in New Delhi.

In 1986 he received a National Award from the President of India for outstanding work in the rehabilitation of persons affected by leprosy. In 1988 he presented a paper on rehabilitation at the XIII International Leprosy Congress in the Netherlands.

In 1993, Dr. Gopal received his Ph.D. in rehabilitation from Ranchi University in India. That same year, he presented a paper on rehabilitation at the XIV International Leprosy Congress in Orlando, USA. It is interesting to note that when Dr. Gopal was invited to be a participant in the Pre-Congress Workshop in Orlando where half of the participants were individuals



Dr. Gopal celebrates Mahatma Gandhi's birthday with students in a leprosy village.
Photo by Pamela Parlapiano

affected by leprosy, it was not initially known that he had had leprosy himself. He was recommended to participate in the workshop because of his experience in social work. The organizers were very happy to learn that he also had the expertise of having had leprosy himself.

It was at the Congress in Orlando that the seeds were laid for the establishment of IDEA, which was officially founded at a meeting in Brazil in 1994. Dr. Gopal was a founding member and elected IDEA's President for International Relations. In this capacity, he represented IDEA in countless international meetings. In 1996, he was elected a member of ILEP's Medical-Social Commission. In 1997, Dr. Gopal established IDEA India.

In 1997, Dr. Gopal stood alongside UN Secretary-General Kofi Annan, along with other dignitaries, to launch the Quest for Dignity Exhibit, a joint partnership between IDEA, WHO and The Nippon Foundation. This Exhibit went on to travel to many countries and portions were translated into several languages in-



(Left to right): Jose Ramirez, Jr., Lian Law and Dr. P. K. Gopal in front of the U. S. Capitol building in Washington, D.C., 1996. Photo by Pamela Parlapiano

cluding French, Italian, German, Portuguese, Chinese and Hindi. In 1998, Dr. Gopal was elected a Council member of the International Leprosy Association. That same year, he presented two papers on rehabilitation at the XV International Leprosy Congress held in Beijing, P.R. China. In 2000 he was invited to chair the WHO-AIFO Workshop on Rehabilitation at WHO Headquarters in Geneva. That same year, he accepted AIFO's Award Raoul Follereau together with Jose Ramirez, Jr., on behalf of IDEA for the organization's role as an agent of social change.

In 2001, Dr. Gopal received the Wellesley Bailey Award from The Leprosy Mission International in London.

In 2001-2002, Dr. Gopal worked hard to identify and assist two women from India in getting visas to participate in the First International Conference on Issues Facing Women Affected by Leprosy, held in Seneca Falls, New York. He supported these two women as they faced humiliation and discrimination in the visa application process. They were not granted visas. However, Dr. Gopal worked with them to organize the first Women's Empowerment Workshop in India that, for the first time, provided a platform for women affected by leprosy in India to meet and discuss the discrimination that they faced.

In 2004, Dr. Gopal received the FESCO (Foundation for the Encouragement of Social Contribution) Award from The Nippon Foundation, which was presented by Their Royal Highnesses, the Prince and Princess Hitachinomiya. He was selected because of "the brilliant way he has taken his life's difficulties and crafted them into a successful movement that is having strong, concrete effects on those around the world who have been affected by leprosy."

In 2005, Dr. Gopal initiated a nationwide survey to identify the leprosy colonies in India. Through this survey about 850 self-settled leprosy colonies in 23 States were identified. Data concerning the living conditions of the residents was collected.

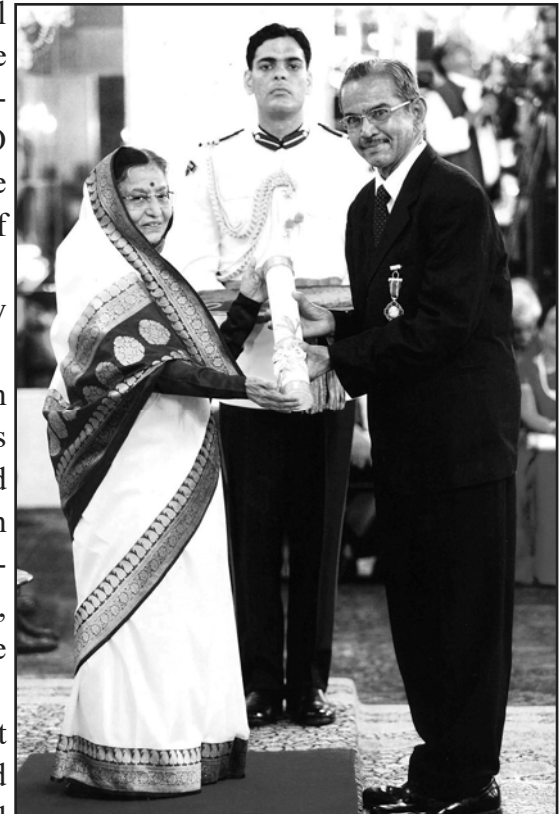
In 2005, Dr. Gopal organized the first National Conference on Integration and Empowerment of People Affected by Leprosy and created the National Forum, of which he was elected Chairman. In 2006, he organized the Second National Conference on Integration and Empowerment of people affected by leprosy at Vigyan Bhavan, New Delhi, with the Vice President of India, Hon. Shri. Bhairon Singh Shekhawat as the Chief Guest at the inauguration.

Between 2005 and 2010, Dr. Gopal was integrally involved in the successful effort that resulted in the UN Human Rights Commission adopting guidelines to end the discrimination against persons affected by leprosy and their family members.

In 2007-2008, IDEA was responsible for organizing 25% of the plenary sessions for the International Leprosy Congress in Hyderabad, as well as a training session on eliminating stigma. Dr. Gopal was integrally involved in this process as well as the planning of other aspects of the Congress, including the participation of 100 individuals affected by leprosy from India.



Dr. Gopal with his family. Collection of Dr. Gopal.



Dr. Gopal receives the Padma Shri Award from the President of India, Her Excellency Pratibha Patil, on March 22, 2012.

Dr. Gopal was integrally involved in this process as well as the planning of other aspects of the Congress, including the participation of 100 individuals affected by leprosy from India.

In 2008, Dr. Gopal worked to make the Parliament aware of the needs of people affected by leprosy and a Petition was submitted to the Parliament.

In 2010, Dr. Gopal worked closely with WHO to identify participants and organize a meeting in Manila to develop guidelines to strengthen the participation of persons affected by leprosy in leprosy services. That year he also participated in the WHO South East Asia Region National Programme

Managers Meeting in Colombo. In 2011, he participated in the WHO South East Asia Region National Programme Managers Meeting in Myanmar.

These are only some of Dr. Gopal's professional accomplishments. Over his career, Dr. Gopal directly influenced the lives of thousands of individuals affected by leprosy in India and worldwide through his efforts to promote social and economic justice. Children of persons affected by leprosy, supported by the IDEA India Scholarship Fund, have become doctors, nurses, engineers, and information technology professionals.

Not only did Dr. Gopal insist on the basic rights of individuals affected by leprosy and their families at the highest levels of government, he implemented programs that served to break the cycle of poverty and social exclusion so often associated with leprosy.

In 2016, Dr. Gopal's autobiography, "From Erode to the United Nations: The Memoirs of Dr. P.K. Gopal," was published. In it, he described the "Dignity Check List" that he developed.

"In a few years, I had developed a socio-economic rehabilitation model for people affected by leprosy. Over time, our efforts and work on this model began to draw the attention of social work departments of colleges and universities, both in India and abroad. Social work students who were pursuing their post-graduate or doctoral research programmes were interested in studying and analyzing our model. I received students from social work colleges for placement in my department. Through the years, I streamlined the process, which started with receiving the patients with dignity.

1. When you meet a patient, acknowledge his/her presence with a smile.
2. Offer him/her a seat.
3. Ask him/her what you can do for them? How can you help them?

First listen patiently to what they have to say and then ask the questions."

Dr. Gopal noted: "This checklist was designed to make people feel human and wanted." It was based on his personal experience.

Dr. Gopal's life was the epitome of dignity. He will be greatly missed. However his legacy will continue through his wife, daughter and granddaughter, IDEA members

around the world, and thousands of men and woman who received IDEA India Scholarships to ensure that each person diagnosed with leprosy is afforded their right to live productive lives with dignity.

On a personal level, Dr. Gopal was one of the kindest people I have ever met. His kindness, gentle spirit and friendship enriched my life, the lives of my family, and the lives of countless other people throughout the world.

Aloha, Dr. Gopal, until we meet again.

Anwei Skinsnes Law

President for Heritage & Education, IDEA

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