

# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

JAN-JUNE  
2017  
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**Dr. James L. Krahenbuhl (1942-2017)**  
Remembering Dr. Krahenbuhl Page 3

# CONTENTS

Jan-June 2017 Vol. 64-23

Remembering Dr. James Krahenbuhl <i>Tom Gillis</i> .....	3
Cristiano Claudio Torres – Citizen of the World.....	4
My Family at Losheng Sanatorium Taiwan <i>By Shu-Lin-Lin</i> .....	5
Life Inside Louisiana's Leprosy Quarantine Was Tragic and Inspirational <i>Gray Chapman</i> .....	6
Remembering Olivia Robello Breitha <i>By Lorenzo DeStefano</i> .....	9
Coke Bottle Garden Returns to Carville <i>By Tom Adams</i> .....	10
The Global Partnership for Zero Leprosy .....	12
Hansen's Disease Clinics.....	15

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## Remembering Dr. James L. Krahenbuhl (1942—2017)

**James L. Krahenbuhl**, Director (retired) of the National Hansen's Disease Programs (NHDP) in Baton Rouge, LA died in Palo Alto, CA on July 29, 2017 of complications from non-Hodgkins Disease lymphoma. He was 74. He was born October 7, 1942 in Appleton, WI and grew up in nearby Menasha. Jim is survived by Betty, his wife of 51 years, Jeff, their son, his wife, Rebecca, and their daughter, Amber who currently reside in Fremont, CA.

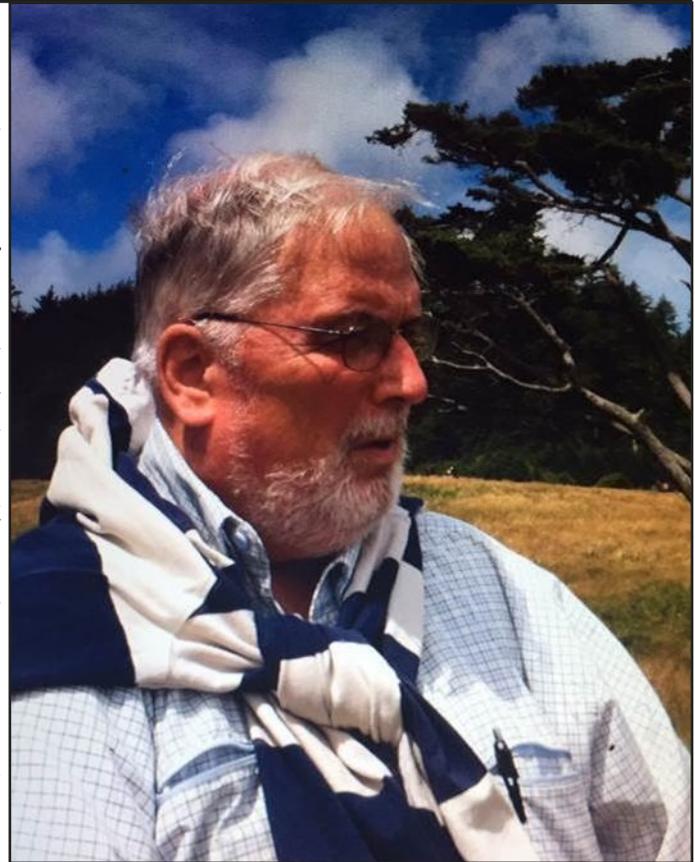
Jim once told me his interest in the sciences was sparked during classes in parasitology where he found beauty in the form and function of microorganisms. He received his bachelor's degree in Zoology as well as his M.S. and Ph.D. in Medical Microbiology from the University of Wisconsin. His working career began at Stanford University and the Palo Alto Medical Research Foundation around 1970. During these early years his focus was on the immune response in infectious diseases and cancer. As his interests evolved, he turned his attention to a seminal cell of the immune system, known as the macrophage. During his 35-plus years at the bench leading research groups at Stanford and then the NHDP, he helped solidify our understanding of how the macrophage ingests and destroys intracellular pathogens, such as *Mycobacterium leprae* (leprosy), *M. tuberculosis* (tuberculosis) and *Toxoplasma gondii* (toxoplasmosis).

After a productive career and many awards as Chief of the Immunology Research Department at the NHDP, Jim took over as Chief of the Laboratory Research Branch. During his tenure the laboratory expanded its research portfolio to include drug discovery for tuberculosis. The TB work was critical as a global threat was emerging leaving people facing TB infections that were resistant to all common antibiotics used to treat TB. Recognizing the unique resources at the NHDP for managing leprosy and providing state of the art research capabilities, Jim became an outspoken and effective advocate for the program as he transitioned to become its 12th Director. During his tenure as Director (2005-2013), he made multiple trips to Washington to educate any and all who would listen.

With Jim's death we have all lost a great friend, scholar and raconteur. Personally, I will remember him for his wit and candor but mostly for his passion; whether it be in pursuit of a scientific truth, the best performance of Beethoven's Ninth or the best coleslaw recipe in the country. While Jim liked playing the curmudgeon, his interest in others was evident in his enthusiasm mentoring younger scientists. He also was a purveyor of sharing and discussing good books and he possessed a strong sense of loyalty.

Jim and Betty were best friends who enjoyed each other's company, shared a passion for places like Vienna, Switzerland, San Francisco, Carmel, Yosemite and Glacier National Park. They especially enjoyed hiking and camping in the redwoods and beach walking. Jim was preceded in death by his parents, Roy and Mary Krahenbuhl, of Menasha and his one sibling, an older brother, Tom. A Memorial Service was set for September 9, 2017 at the Church of the Nativity in Menlo Park, CA. The family requested no flowers but donations can be made to the Leukemia and Lymphoma Society ([donate.lls.org](http://donate.lls.org)).

-Tom Gillis



## Cristiano Claudio Torres – Citizen of the World 1939—2017

*"Now I consider myself a  
citizen of the world."*

-- *Cristiano Torres at an IDEA  
workshop in  
Fontilles, Spain, 1997*



**Cristiano at the International  
Leprosy Congress  
Hyderabad, India, 2008**

“Friends of IDEA: It is with much pain that I communicate the death of our leader Cristiano Torres. He has collaborated in many international IDEA events.

A hug” --Artur Custodio Moreira de Sousa, Vice -- Coordenador Nacional do MORHAN, January 23, 2017

Cristiano Claudio Torres was born in 1939 in the Prata Hansen’s Disease Community in Brazil. He was taken away from his parents and placed in a “Preventorio” – a nursery where children of people with Hansen’s disease lived. When he was five, he showed signs of the disease and eventually was sent to the Prata with his parents. Involved in politics and social movements at an early age, he helped distribute a protest newspaper called *Clarim (Clarion)* that was printed in his house, which criticized the conditions at Prata. He later became involved in an effort to enable people in the Hansen’s disease community to obtain a high school education. He was one of the earliest members of MORHAN – The Movement for the Reintegration of Persons Affected by Hansen’s disease, and was National Vice-Coordinator of the organization. He was a founding member of IDEA. Cristiano did extensive research and wrote a book on the Hansen’s disease communities in Brazil and presented papers at national and international conferences.

“So sad to hear about our brother moving on to another world to continue his advocacy. Magdalena and I always looked forward to hearing his stories of others overcoming huge obstacles, but it was he who overcame and showed us the journey. We miss you Cristiano.”

-- Jose Ramirez, Jr.

“... This month for me will be the month of Cristiano. I met Cristiano 30 years ago, when I was still trying to understand the universe that came along with the militancy movement for the rights of people affected by Hansen’s disease. His life taught me almost everything . . . I wish that his life, like that of so many, is not forgotten, and continues to light our future paths . . .”

-- Artur Custodio Moreira de Sousa

## **My Family at Losheng Sanatorium Taiwan**

**By Shu-Lin-Lin**

Even though I did not have Hansen's disease, I grew up at the National Leprosarium for Leprosy known as LOSHENG Sanatorium Taiwan. The following is a family story I share on behalf of my mother, Shuchou Furi, who has been President of IDEA Taiwan since 2013.

My father, Shu-Yanming, was born on July 6, 1933 at Nanyang County of Henan, Mainland China and migrated with his parents to Taiwan at age 12. At age 27, while serving in the Taiwanese Army he was diagnosed with HD and immediately sent to Losheng Sanatorium in 1960. Mother was born on July 6, 1944 in Hualien of Eastern Taiwan. At age 17 she was diagnosed with leprosy and also sent to the sanatorium to live a segregated life. She arrived at Losheng one year after father and they married at St. Hope Church one year later, raising four children.

My oldest sister, Chan-Chan, was born in 1967 quietly in a bathroom as children were not allowed at the sanatorium. Fearing the possibility of contamination, though the disease has been proven not to be hereditary, she was sent to a "love orphanage" and raised by Reverend Sun Li Niang.

As the second child I was born in 1968, but this time mother decided to hide me in the sanatorium until my early childhood. This gave me the opportunity to be embraced by all of the residents of Losheng as their child and witnessing the physical, emotional and spiritual endured by all. I recall the people of Losheng as hopeful and loving, and the grounds as beautiful and pure. A common theme at Losheng, then and now, was that of a powerful and cohesive force intent on a future free of discrimination.

My two younger siblings, Li-Li born in 1969, and brother (the miracle child), Qiao Do, born in 1989, were raised by mother in the sanatorium, a special occurrence as children born there were routinely sent to orphanages.

The four of us saw the hardships experienced by our partners and others at Losheng, but we also learned about advocacy. Our parents, fearful of stigma and discrimination, were always there to protect us from being bullied and providing us with warm love, an affection mother lost in her youth due to poverty and institutionalization. Father tried very hard to be a good provider and once left the sanatorium to care for aging soldiers and earn enough money to lessen our own hardships.

Watching my father take the lead in protests when the Taiwanese government tried to close Losheng filled with elderly persons formerly segregated from society has left a lasting impression with me. Also, seeing my mother transforming her bitter past by writing and singing songs of dignity and respect and fighting for the rights of all who were involuntarily sent to Losheng has touched my heart and made me burst into tears of joy. Her story and accompanying pain has touched many and recently she was interviewed by the Taiwanese Ministry of Culture to record and document her story in the national memory bank.

The people of Losheng will never stop seeking the death of stigma and glow of acceptance.

## Life Inside Louisiana's Leprosy Quarantine Was Tragic and Inspirational

The stigma and lack of understanding of the disease shaped every facet of life for patients there, who started their own businesses, founded a newspaper, and used their own currency.

—Gray Chapman

*Published October 2017 on Vice.com, All photos by the author*



The drive out of New Orleans on I-10 West toward Iberville Parish snakes across wetlands carpeted in velvety green algae. Eventually, the marshes give way to truck stops, a Tanger Outlet, a Logan's Roadhouse, and a flat, unremarkable highway, punctuated with the occasional desiccated husk of an armadillo. Beyond the interstate, there's the ugly metallic tangle of industrial plants. Beyond those, fields of sugarcane. And beyond that, tucked in a bend of the Mississippi River, there's a fenced-in, guarded compound that's borne many names over the years: the Louisiana Leper Home, the National Hansen's Disease Center, now the National Hansen's Disease Museum. Throughout its history, most people—

locals and patients alike—have just called it Carville.

Carville's verdant 350 acres, originally hunting land belonging to Houma natives and subsequently a working sugar plantation, welcomed its first patients as the Louisiana Leper Home in 1894. "After years of effort, Louisiana has now reached a solution of its leper problem and is now gathering all its lepers, several hundred in number," reads an 1895 dispatch from the *Catholic Standard* newspaper. In light of the surrounding community's disgust for having a "leper colony" in their midst, the newly established Leper Board surreptitiously ferried in their first seven patients by river barge in the middle of the night.

Over its century-long tenure as a treatment facility, research center, and quarantine, Carville was home to more than 5,000 patients, many of whom were forcibly quarantined and institutionalized by law and spent the majority of their lives inside the compound. A thousand deceased patients are still there, buried on-site.

Until 1960, any American diagnosed with leprosy was legally mandated to sever their connections to society and live in confined isolation until receiving medical clearance—a rarity and a gamble until the current multi-drug therapy treatment for leprosy (now referred to as Hansen's Disease) was developed at Carville in the 1950s. Upon entering Carville's iron gates, patients reported to their modestly furnished dormitory rooms, received their government-issued clothing, and, for the most part, surrendered their autonomy and their lives as they knew them. (The facility's rules included a curfew and of course forbade patients from "leaving their enclosure.") None of them knew when or if they'd ever return home.



The facility, which still housed residents up until a few years ago, now acts as the National Hansen's Disease Museum, operated under the Department of Health and Human Services. Curator Elizabeth Schexnyder grew up in the area and joined as a volunteer in 1997, when there were still roughly 150 patients in residence. She is tasked with preserving, archiving, and exhibiting the roughly 22,000 artifacts the facility has accumulated over the years, from moulds of patients'

disfigured hands to obsolete medical supplies like wicker coffins and rickety hand-cranked wheelchairs. As a museum, Carville's purpose is to honor patients and, primarily, to educate the public. It's a Sisyphean undertaking, demystifying a disease that has been stained with meaning and myth (for the records, limbs do not "fall off"). For millennia, leprosy has been universally stigmatized as a gruesome curse and a public menace, quite literally adding insult to injury for those who suffered it. "Many of us learn about leprosy from the Bible or some other religious outlet," Schexnyder tells me. "It had a stigma of being more than a disease, more like a curse from God or a judgment. Like if you hadn't sinned, you wouldn't have this problem."



That stigma, coupled with a lack of understanding about how the disease is contracted, shaped every facet of life for patients at Carville, especially before the scientific breakthroughs of the midcentury. Money within the property was regularly sanitized with chemical fumigation, and patients were forbidden to engage with the traveling peddlers who sidled up to Carville's fence, for fear of circulating unclean cash. (Schexnyder tells me that other leprosaria around the world even developed their own unique currencies to reassure surrounding communities that tainted coins wouldn't spread.) Outgoing mail was baked in a 300-degree oven for half an hour before leaving the grounds. Even Carville's layout was designed to keep patients sequestered from staff. "We have two of everything here," Schexnyder

says: two golf courses, two infirmaries, two cafeterias, two sides of a campus divided (initially by a wall, and later, a hedge). Even the seating inside Carville's chapel was segregated to separate the sick from the well. Two confessionals flank the altar, one for personnel and one for patients. Throughout the facility's long history, no employee ever contracted the disease.

Fear was the salt in the wound of a leprosy diagnosis, and it meant that patients were ostracized from the rest of the world as their families were ripped apart. Schexnyder tells me that most of their patients were in their 20s and 30s when they arrived at Carville, with twice as many men diagnosed as women. Children under the age of 16 weren't allowed on the property for visitation. Schexnyder tells me about one woman whose young daughter was regularly smuggled in to see her by hiding underneath a rug inside the family's car.

Patients frequently assumed pseudonyms at Carville to protect their families back home, but if a diagnosis became community knowledge, those families often suffered. "Marriages ended, businesses failed, siblings were taken out of school," Schexnyder explains. She regularly encounters visitors who discover Carville after researching their own genealogy. "I get to talk to a lot of patients' families who are finding out they had relatives here... there's usually one family member who was tasked with the memory and told not to give it up until they were on their death beds." Sometimes, research calls into question a family narrative that just doesn't add up: a great-grandfather who supposedly moved to Cuba or took a job on a railroad. "Then they find out he was a patient at Carville. He died here. He might even be buried here."



Often, a community's reaction to a diagnosis turned violent. Schexnyder points to a folk-art painting on the wall, a modest cottage engulfed in flames under a night sky. "This took place 30 miles downriver. The artist's wife was a patient here as well. This is what happened to her family home."



Even in death, stigma haunted patients: quarantine laws applied to corpses, too. Carville was required to disinfect dead bodies, seal them inside a metal-lined coffin, solder them shut and lock them inside a tight wooden box. Should a patient's family wish to bury him or her back home, the body could only be transported with permission from each health department of each state it would travel through. That's one of the reasons Carville's two cemeteries are so full, Schexnyder tells me. Much of the time, it was just too difficult to send people home.

Carville was often witness to agony, but it was also a place where life continued to unfold anyway: a functioning civilization in miniature. As the facility became globally recognized, other nations sent patients to Carville for treatment. "It was

like a little United Nations," Schexnyder says. Enterprise was encouraged by the government and thriving among the patients, many of whom had previously served as their family's primary breadwinner. One patient opened a barber shop; another worked as an on-site seamstress. Johnny Harmon, a patient who later self-published a memoir titled *King of the Microbes*, acted as a sort of unofficial Carville documentarian, taking pictures and selling them on 35-millimeter slides as souvenirs to visitors. The patient-produced newspaper, the *STAR*, has a prolific archive and is still maintained today.

Faced with an open-ended exile and a fair amount of free time, Carville patients reconstructed facsimile versions of their old lives. A notorious hole in the fence allowed some to periodically sneak out and duck into town for a beer. Holidays were taken very seriously, Schexnyder says—especially Mardi Gras, celebrated with a parade through Carville's two and a half miles of covered walkways so that bedridden patients could still see the festivities from their infirmary rooms. One of the most striking artifacts on display in the museum is a small float stylized as a red Chinese dragon. From a distance, it looks like a miniaturized version of one you might see promenading through the French Quarter on Fat Tuesday. A closer look, though, shows that the float is constructed from the occupational therapy department's casting and bandaging material. It's precisely sized and shaped to fit over a wheelchair.



The parades, the trophies from softball games (all home games, of course), the homemade costumes—Carville's museum is a pretty incredible testament to the human spirit. It's also disturbing proof of how fear, misinformation, and stigma can metastasize around illness and those who suffer from it. Carville patients not only fought a life-altering diagnosis, they were forcibly cast out by their own communities. For those lucky enough to return home, the outlook wasn't much brighter. Even a patient given medical clearance and allowed to return home faced "new rules of life," wrote Dr. Faget, the medical officer in charge at the time, in a 1943 edition of the *STAR*. "He must not expect to go out into the world and cope with his fellow man on equal footing. It may be difficult for many patients to adapt themselves to these conditions on the outside after their long siege of institutional confinement."

Faget goes on to warn about the risks of taxing the body or overindulging for patients with arrested cases. "You do not want the misfortune of having to return for a second treatment," Faget continued. "It will be more difficult the second time."

# Remembering Olivia Robello Breitha

By Lorenzo DeStefano

Olivia Robello Breitha, born in 1916 on the island of Kauai to Portuguese immigrant parents from the Azores, has been gone from here since September 28, 2006. As a resident of Hawaii's legendary Hansen's disease settlement of Kalaupapa, Molokai, her lifelong struggle with authority is over. But her mission to have us remember the more than 8,000 people who lived and died in Kalaupapa continues.

I was 37 when I learned from my mother that we had a relative with leprosy. Olivia Robello grew up in a tight-knit, hardworking community where family pride and the magnetic pull of assimilation often clashed. People kept anything potentially embarrassing locked tightly in the closet. If word ever got out that someone in the family had contracted such a dreaded disease as leprosy it would have a serious effect on their social standing, the way they were treated at work, at school, even in church.

For those of us who spent time with her over the years, as family and as part of her large network of friends, knowing this lady was a blessing. To me she was not merely a found relative. She was a complex woman who fully lived the life that was dealt to her, all 90 years of it. Through her thoughts and words you will discover that she was not one to succumb to life's difficulties. She met every challenge head on, the small and the immense. Instead of destroying her they transformed Olivia Robello Breitha into the powerfully eloquent social activist she was always meant to be.

As Olivia's cousin and literary executor, I have strived these past eleven years since her death to keep her story alive. There is a relevance to her experience at the hands of the so-called medical experts of her time that serves as a beacon to public health policy-makers to this day and beyond.

Olivia's memoir, "My Life of Exile in Kalaupapa", originally published in 1988, is now available in a newly-designed edition from Honolulu publisher Pacific Historic Parks (<http://www.pacifichistoricparksbookstore.org/olivia-my-life-of-exile-in-kalaupapa.html>). This powerful book chronicles Olivia's personal and medical history from the age of 18, when she was first diagnosed with this long-misunderstood condition. Olivia's memories tell us more about her seventy years of life as Hawaii Department of Health parolee # 3306 than she felt she could ever reveal. Fueled by a streak of righteous determination, she writes with passion of her struggles and, by extension, the struggles of thousands of others against centuries of stigma and fear. She asks us to see her not as societal outcast but as an individual, a person as flawed and as divine as the rest of us, who tried her best to rise above her adversities with quiet dignity.

An unabridged Audiobook, narrated by Deanna Espinas, is available from Audible at [http://www.audible.com/pd/Bios-Memoirs/Olivia-Audiobook/B01MXYSFX1/ref=a\\_search\\_c4\\_1\\_1\\_srTtl?qid=1491457649&sr=1-1](http://www.audible.com/pd/Bios-Memoirs/Olivia-Audiobook/B01MXYSFX1/ref=a_search_c4_1_1_srTtl?qid=1491457649&sr=1-1).

"Shipment Day", my play about Olivia's diagnosis and early treatment in 1930s Honolulu, was first developed at The Road Theatre Company in Los Angeles in 2015. It won Best Play, Best Actress and Best Actor at the Playbuilders of Hawaii New Works Festival in 2016. The Hawaii Performing Art Company/Manoa Valley Theatre (<http://manoavalleytheatre.com/theatre/>) have commissioned a full length version of "Shipment Day" as a world premiere during their 50th anniversary season in 2019.



## Coke Bottle Garden Returns to Carville

Tom Adams, Carville STAR Sous Directeur

**History of Coke Bottle Gardens.** For some time, Elizabeth Schexnyder, Curator of the National Hansen's Disease Museum envisioned the return of a Coke Bottle Garden to Carville. In case you've never heard the story, for years the local Coca-Cola distributor refused to deliver to the United States Public Health Service Hospital at Carville, fearing he would lose customers if word got out. When he finally relented, he demanded the bottles never be returned, meaning there would be no refund of deposits. In response, perhaps in a symbolic act of defiance, the patients planted the Coke bottles upside down to create geometric shapes and line the beds of their flower gardens.

Over the years, these gardens disappeared from the Carville landscape. An interpretive marker and display at the museum remind of this creative use of Coke bottles. However, nothing seemed more likely to attract the attention of visitors than the return of a Coke Bottle Garden to the Carville landscape.



**Getting the word out for bottles - acquisition and logistics strategy.** The quest to recreate the garden began with the search for Coke bottles, lots of Coke bottle. Five to six hundred would be needed to recreate a STAR comparable to the one shown in an iconic photograph of a garden. (photo 1) The need for bottles was promoted whenever possible and while many indicated a willingness to buy and collect bottles, there remained the concern for the logistics of getting the bottles to Carville. When the cast and supporting crew of *Bend in the River* from the Wings Performing Arts Center in Gulfport, Mississippi visited Carville they learned of the need for bottles. Subsequently they became the first significant contributors after accumulating about 200 bottles that were delivered to Carville.



**A Carville STAR pin nets more bottles.** The acquisition of bottles continued with the serendipitous purchase of a Carville STAR pin by Ellen (Ellie) Rutherford in Atlantic, Iowa. (Ellie is a staff member at a Coke museum, the Atlantic Coca-Cola Center, Iowa.) Ellie has a passion for locomotives, and purchased a locomotive pin emblazoned "Pulling for Carville" (photo 2) from a local thrift store.

Her computer search for "Carville" netted the website of the National Hansen's Disease Program, and Elizabeth's name and phone number. Ellie's call to Elizabeth at the Museum answered her questions about this little pin and Carville. When Elizabeth learned of Ellie's connection to the Coke museum in Atlantic, it was reflexive to mention the need for Coke bottles. It happened that the museum was willing to donate about 500 Coke bottles. Ellie emptied and washed the bottles and prepared them for their travel to Carville. (photo3)

**Transport from Iowa to Carville.** Then came the challenge of how to transport from Iowa to Carville. An initial thought was for a 40&8 relay team that could move the bottles from state to state. However, more seren-





dipity occurred when a friend of Ellie, Jim Nordskog agreed to bring the bottles south on his way to Florida. He ended up meeting me in Hattiesburg, MS where we transferred bottles from his vehicle to mine. Photo 4 shows Jim with the 19 cases of cleanly wrapped bottles now well on their way to Carville!

Finally, it was time to deliver the 19 cases (456 bottles) to Carville and begin work on the garden. (Photo 5 shows bottles delivered by Tom and Pat Adams to the Museum



loading dock in Carville.)

**The vision becomes reality.** The designated site for the Coke Bottle Garden showcases a STAR as the centerpiece of an existing walkway near Building 29 and adjacent to the first patient cemetery. Fortunately,



HRSA employee Anthony Sanchez, Jr. and Henry Grass of the Louisiana National Guard had blazed the design phase of the garden and staked out the exact pattern for a STAR. With that done, it was time to get on hands and knees and begin hammering the bottles into the South Louisiana soil, not-so-affectionally known as "black-jack". In this photo, Nationale Carville Star Directeur Red Miller joins Tom (Voiture 1411) and Pat Adams (Cabane 1411) as the points of the STAR near completion.

Ellie and the Coke Museum in Atlantic, a bottle bearing "Atlantic, Iowa" on the bottom was driven into the exact center of the STAR.

In a final construction photo, Red and Tom drive the last bottles into the STAR. Previously, in tribute to



A final photo shows the completed Coke Bottle STAR garden on the walkway. Following settling of sand, there will be some finishing aesthetic touches to the garden. Because it is true that "the real thing" is worth a thousand words or pictures, it is expected that for years the STAR garden will be a tour highlight for those visiting Carville.



# Global Partnership for Zero Leprosy

**The Global Partnership for Zero Leprosy is an association of organizations and individuals committed to ending leprosy, also known as Hansen’s disease.**

## **Background**

Since the introduction of effective multi-drug therapy (MDT) some 30 years ago, the reported prevalence of leprosy has been reduced by more than 95%. In contrast, the number of people reported with newly-diagnosed leprosy has consistently remained above 200,000 per year over the past decade. New scientific advances provide fresh hope that the vision of “zero leprosy” can be achieved. In addition to tools and strategies to effectively diagnose, treat, and prevent infection, achieving zero leprosy requires a strong global partnership aligned behind a common vision. The leprosy community has a renewed sense of urgency to accelerate progress toward this vision and has clarified the need to work collaboratively in innovative ways.

In 2016, the Novartis Foundation and the International Federation of Anti-Leprosy Associations (ILEP) hosted an initial meeting at the World Leprosy Congress in Beijing to build momentum toward a Global Partnership. Soon after, the Novartis Foundation convened a Steering Committee and hosted its first meeting in February 2017. Along with the Novartis Foundation, the Steering Committee included representation from persons affected by leprosy, national program managers, researchers, the World Health Organization, ILEP, and the Sasakawa Memorial Health Foundation. The Committee then engaged the Task Force for Global Health to conduct a stakeholder analysis. During April-June 2017, stakeholders throughout the leprosy prevention and control community were interviewed and surveyed regarding their interest in becoming part of a Global Partnership for Zero Leprosy and their views on optimal structure, governance, and membership for such a partnership.

With this information, the Steering Committee reconvened in August 2017 to develop a blueprint for the Global Partnership for Zero Leprosy and plans for further stakeholder engagement. They also discussed next steps for launching the Partnership.

## **Vision**

The vision for the Partnership is zero leprosy.

## **Purpose**

The purpose of the Global Partnership is to facilitate alignment of the leprosy community and to accelerate effective collaborative action toward the goal of zero leprosy.

## **Principles**

The following principles will guide the partnership:

All decisions, priority choices, funding allocation and actions will support the vision of zero leprosy.

Zero leprosy will not be realized without reducing *M. leprae* transmission. Therefore, a primary focus of the Partnership will be to develop the scientific and technical agenda needed to accelerate detection and prevention of leprosy to interrupt its transmission, and to scale up innovations at national program level. The Partnership will be guided by evidence and reinforced by sharing experience and effective practices.

Zero leprosy includes addressing issues of stigma and discrimination of persons affected by leprosy, their families, and their communities.

The partnership will coordinate action among leprosy stakeholders and seek to minimize duplication of efforts among stakeholders.

The Partnership recognizes and supports ownership of national leprosy programs by national governments and will include representation from national programs in its leadership and decision-making.

The Partnership endorses full participation of persons affected by leprosy, including representation on the leadership team and involvement in working groups and committees. A working definition of “full partnership” will be included in the charter for the Partnership.

Three initial working groups will focus on priorities of 1) setting the scientific agenda and developing priorities for technical, clinical, operational, and implementation research; 2) programmatic innovation, effectiveness, scale-up, and influencing policy; and 3) fundraising and advocacy.

## **Organizational components**

The Steering Committee proposes four major organizational components for the Partnership: membership; leadership team (i.e., executive group or governing board); secretariat; and working groups. After the launch of the partnership, the structure and function of these components will be reviewed within three years, and revised as needed. As working groups will be essential for driving the agenda and ensuring the success of the Partnership, they will be presented first.

### ***Working groups***

Three initial working groups are proposed, based on priorities identified in the 2017 stakeholder survey and subsequent deliberation by the Steering Committee. Membership on working groups is open to organizational and individual members of the Partnership. Working groups can invite to meetings or deliberations specialists who are not Partnership members in order to benefit from their expertise or information. Each working group will include, at a minimum, one member from the leadership team.

*Setting the scientific agenda and developing priorities for technical, clinical, operational, and implementation research*

*Program innovation, effectiveness, scale-up, and policy*

*Fundraising and advocacy*

### ***Membership***



FRONT ROW, L-R: Ann Aerts (Head, Novartis Foundation), Etsuko Kita (Chair, Sasakawa Memorial Health Foundation), Arielle Cavaliero (Leprosy Project Manager, Novartis), Tanya Wood (CEO, ILEP), Ernesto Villalon (Program Manager, Philippines National Leprosy Program).

BACK ROW, L-R: Mark Rosenberg (Former CEO for Global Health and Facilitator of meeting), Jan van Berkel (President of Board, ILEP), Erwin Cooreman (Team Leader for Leprosy Program, WHO), Jose' Ramirez, Jr. (IDEA International), Peter Steinmann (Epidemiologist for Neglected Tropical Diseases), Edward Vela (Senior Advisor to SMHF).

Membership is open to organizations and individuals that are committed to zero leprosy and that support the principles, objectives, and activities of the Partnership. Members of the Partnership are expected to attend annual or semi-annual Partnership meetings and otherwise support the work of the Partnership through their own ongoing initiatives. They are encouraged to participate in a working group.

Organizational membership is open to government agencies; non-governmental organizations; multilateral organizations; organizations of persons affected by leprosy; foundations and donors; and universities, research institutes, and professional societies. In the event that a vote of the membership is required, all organizational members shall be considered “voting members” with the exception of those (such as WHO) whose constitution or bylaws require that they be considered as “observers.”

#### **Secretariat**

A secretariat will be established to support the work of the Global Partnership, its leadership team and working groups. The location and organizational host of the secretariat have not yet been finalized, but it should be a legal entity that can enter into contracts on behalf of the Partnership. As with other global partnerships and alliances focused on neglected tropical diseases (NTDs), some secretariat functions may be dispersed among members of the leadership team, at least initially.

Responsibilities of the secretariat include:

- Support the leadership team and facilitate its meetings and activities
- Support the working groups and facilitate their meetings and activities
- Organize an annual or biennial Partnership meeting as well as other ad-hoc meetings
- Document processes and functions of the Partnership and facilitate its management
- Provide frequent, coordinated communications to Partnership members and affiliates, as well as to external partners
- Develop and maintain a robust communications activity, including a website for the Partnership
- Advance and coordinate fundraising for the Partnership and for ongoing secretariat functions, in close collaboration with the working group on fundraising and advocacy.
- Liaise with Uniting to Combat NTDs, other NTD groups and reference centers, and other relevant infectious disease communities in global health.

#### **Next steps**

Steering Committee members will circulate this document among their constituents for comment and input.

Steering Committee members will also discuss the document and seek input at upcoming meetings (e.g., NNN, Dakar, Senegal, 28-30 September; ILEP, Würzburg, Germany, 16-20 October; European Congress on Tropical Medicine and International Health, Antwerp, Belgium, 16-20 October; and COR-NTD, Baltimore, USA, 3-4 November).

With feedback from the leprosy community, the Steering Committee anticipates that the Partnership will be announced early in 2018 if not by the close of 2017.

**\*\*\* ATTENTION \*\*\***

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## HANSEN'S DISEASE CLINICS

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7<sup>th</sup> Floor MOT

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# The Star

RADIATING THE LIGHT OF TRUTH  
ON HANSEN'S DISEASE

## GET TO KNOW THE FORTY & EIGHT

The **Forty & Eight**, an honor society of veterans created in 1920 and **The STAR's** primary funding organization, draws its origin from World War I. Millions of American soldiers in France were transported to the front in narrow French box-cars, called "Voitures," which would only hold 40 men or 8 horses. Remembering the close brotherhood of those box-car days, **La Societe des Quarante Hommes et**

**Huit Chevaux (The Society of 40 men and 8 Horses)** was formed and local Voitures began organizing as outstanding Legionnaires were invited into membership. Membership is still by invitation only.

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



## FACTS ABOUT HANSEN'S DISEASE

### What is HD?

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

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

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

### Where is HD Found?

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

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

### How Does HD Spread?

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

### How is HD Treated?

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

NHDP SERVICES Website: [www.hrsa.gov/hansens](http://www.hrsa.gov/hansens)