

CARVILLE STAR & MUSEUM

By Joyce Willis, Nationale Carville Star Chairperson

First of all, let me introduce myself to you—my name is Joyce Willis, a proud member of Cabane 506 de North Carolina, and I want to thank Madame La Presidente Nationale Sandy Wood for giving me the opportunity to serve as Nationale Carville Star Chairperson this year. She has chosen the Carville Star Museum in Carville, Louisiana, as her fund raising program, and it my pleasure to give some background information about the museum.

Focus was first placed on the Carville Museum as a project by Chef de Chemin de Fer Passé Bob Kaseman (2002). He visited the museum during his term and saw first hand the extreme need for refurbishing and updating the materials. The building itself was in dire need of repairs and to this effort, Chef Kaseman led the La Societe of the Forty & Eight, with some help from the Dames of La Societe de Femme, to raise \$10,000.00 for the museum. Then in 2005, funds were raised through Chef de Chemin de Fer Passé Mac McCarthy to install a new banner and a permanent sign in front of the museum. In the following 3 years, during Nationale Directeur Passe Mike Wood's leadership of the Carville Star Committee, a beautiful flag was placed in front of the museum with the Forty & Eight emblem on it to show the organization's sponsorship of the museum and monies were raised for a beautiful monument. In its efforts to preserve more of the history of Carville, the Forty & Eight funded a large monument that was placed in the cemetery there with the names, nicknames, or just initials of the first 136 patients who died at the Leprosarium as a result of the disease and the Nuns of the Sisters of Charity who dedicated their lives to caring for the residents between 1894 and 1922. Real names were rarely used due to the stigma associated with leprosy and the hardship that it would cause their families.

Donations have continued to come into the museum's account to restore historic paintings, to purchase preservation materials to keep documents and artifacts safe, and any other needs that might arise in the day-to-day operation of the museum. In addition, Carville Star pins have been donated to the museum to give visitors as souvenirs in return for donations. We are very fortunate to have a professional curator on sight, Elizabeth Schexnyder, and she diligently works to oversee the museum, provide daily tours, and constantly update equipment needed to provide the most accurate and informative materials about the museum.

The National Hansen's Disease Museum in Carville, just across the Mississippi River from White Castle, Louisiana, stands as a living and ever-expanding tribute to the patients and health care professionals who lived through a very difficult life dealing with Hansen's disease, more commonly known as Leprosy. The National Leprosarium there served as a place of quarantine for Hansen's disease patients beginning in 1894 when boatloads of people affected with the debilitating illness were dropped off on the banks of the

Mississippi to begin their life of exile. The Leprosarium has been on the National Register of Historic Places since 1992.

The museum's artifacts chronicle the life of the patients at Carville, and displays information on the research and development of medical treatments for Hansen's Disease that have come to fruition since those first residents arrived in 1894. There are artfully displayed exhibits of photos, relics that have been discovered on the grounds, and inventions of residents who created items out of necessity to compensate for the physical limitations caused by the disease. There is a tastefully-created replica of a patient's room as it would have been in the 1940's and lots of examples of patient's stories and artwork.

Donations from La Societe have also helped Elizabeth, as curator, to obtain the necessary equipment to develop an audio self-guided tour of the grounds for walking or driving.

Also chronicled in the museum is the story of Stanley Stein's development of THE STAR publication. At first, the publication was printed on the grounds of Carville, but with the death of those who had worked so diligently to make the publication a reality and the advancement of technology, it became more cost-effective for the Forty & Eight to take over the publication. The museum provided a complete history of the hardships that had to be overcome in order for the STAR to be issued to the general public. Again, the stigma of Hansen's disease played a huge role in how people viewed the disease. The public was scared to death of 'catching' the disease if they touched anything that had been handled by a patient.

Dr. James Krahenbuhl, director of the National Hansen's Disease Program center in Baton Rouge and his staff, along with the expertise of THE STAR Managing Editor Jose Ramirez, who was himself a resident at the Carville Leprosarium, partner with the Forty & Eight Carville Star Nationale Directeur along with Elizabeth and Simeon Peterson, Editor & Ambassador for the Museum and still a resident of Carville more fondly known as "Mr. Pete", arrange a meeting or teleconference 2 times a year to discuss the material for the next issue of THE STAR. The information gathered for each issue is priceless to the 14 clinics within the United States and the 50 countries around the world that are treating Hansen's disease, in order to keep them abreast of the latest research and discoveries about Hansen's disease in hopes that one day there will be a vaccine to completely prevent the disease.

This is where some of the other areas within the Carville Star Program come into play. Voitures and/or Cabanes can purchase as many subscriptions of the STAR as they wish for \$2.00 per subscription (2 issues a year) and designate a clinic or country to send them to (*Buy a Clinic* or *Buy a Country*), or to keep for their own personal information for their voyageurs and dames. The *Buy a Clinic* program was begun by Nationale Directeur Passe George Willis (2008-2011) in order to include the 14 clinics in the United States in the Carville Star family and make their existence known to a larger group of people than ever before. To qualify for the *Buy a Clinic* or *Buy a Country* recognition and certificate, the donation must be for at least \$50.00. These subscriptions that are put into treatment centers give information that would not be obtained otherwise in some of the

'third world' countries. The money for these subscriptions has to be sent to the Nationale Directeur Carville Star Joseph Steil. Donations to the STAR general maintenance fund can also be sent to Directeur Steil and be designated "*In Honor Of*" or "*In Memory Of*" a person that is or has been very special to their Voiture and/or Cabane.

So in closing, I can't stress enough how important it is to our country's history to keep the events that occurred in Carville, Louisiana alive, from that fateful night in 1894 when the first Hansen's disease patients were taken to an old antebellum plantation that had been reconfigured both to care for and isolate them from the rest of the world until now. Research at the center ultimately provided breakthroughs that made medical treatment effective and quarantine unnecessary. Visitors to the museum and grounds around the museum learn that Leprosy is not the highly contagious curse that people once thought. The majority of visitors always want to go back, and if they do, they always learn more. This is why it is so important for us to continue to support the Carville Star Program and especially the Carville Museum, Madame La Presidente Sandy's special project. Please send your donations specified to the Museum Fund—Dames should send their donations for the Museum Fund to *Cabane Nationale* with *Museum Fund* in the memo line, and Voyageurs or Voitures who wish to support Madame La President's project should do the same. Otherwise, Voitures and Voyageurs should please send their donations to Directeur Steil. Madame La Presidente is trying to raise \$5000.00 for the museum, and with a unified effort, I know her goal can become a reality. I thank you, in advance, for the support that will come flowing from our Voitures and Cabanes!