Public Health Chronicles

COMMUNITY AND CONFINEMENT: THE EVOLVING EXPERIENCE OF ISOLATION FOR LEPROSY IN CARVILLE, LOUISIANA

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The 19-year-old, recently engaged New Orleans woman was at the peak of her youth in the Christmas season of 1927 when she noticed pale, rose-colored spots on her legs—spots indicative of leprosy. Formally known as Hansen's disease, leprosy is a mildly communicable chronic bacterial infection typically acquired in childhood that, over a period of years or decades, affects one's peripheral nerves, skin, upper respiratory tract, and eyes, resulting in blindness, disfiguring skin lesions, and absorption of the bones and cartilage of fingers, toes, ears, and noses.[1] Beginning in 1921, leprosy was, in all states but New York, grounds for isolation and treatment at the Public Health Service Hospital in Carville, Louisiana.[2,3] Assured of a rapid cure by her fiancé, in January 1928 the newly-diagnosed woman entered Carville.

She left without a word except to her closest family members and a single friend, who would keep the secret of her diagnosis. Thus, "Betty Parker" was created. She would hide her true identity from all but the most intimate friends within the confines of Carville. The loss of identity seemed, initially, temporary; Parker was unable to predict she would be confined to Carville for the next two decades of her life.

Parker's story is framed by unfolding medical as well as social and political change over the course of the decades immediately before and following World War II. From the 1920s through the 1950s, from 1,500 to 5,000 people in the United States were estimated to have Hansen's disease (in contrast to 108 known new U.S. cases since 1999).[4] When Parker was first confined, the sole treatment for leprosy was Chaulmoogra oil—a foul smelling and largely ineffective tree extract that patients could opt to take either orally (at the price of extreme nausea) or by injection (at the risk of developing local abscesses). When Parker arrived at the start of the Great Depression, those confined at Carville shared little in common other than a sense of isolation and hopelessness. With the dawn of the antibiotic age in the early 1940s, however, the therapeutic prospects for those with leprosy were radically altered. With new hopes for recovery, the experience of confinement at Carville consequently changed.

But therapeutic advance alone does not explain the shifts in the patient experience at Carville during the 1940s. A sense of community, after all, implies not just notions of association or connection to other people, but also common understandings of the fundamental political, social, and economic rights and entitlements of American citizens. Thus, the changing social context of the nation—from Depression, to World War, to Cold War—interacted with therapeutic change to profoundly shape the experience of community and confinement at Carville.

CARVILLE AS ASYLUM: THE QUEST FOR SECURITY IN THE DEPRESSION ERA

In the 1920s, Carville carried all of the familiar markers of a community, including churches, shops, a theater, a morgue, a cemetery, and even a jail.[2] It was not run like a typical hospital, and despite compulsory confinement and demeaning rules, it was not an entirely closed institution. Patients were granted yearly leave, and although it was difficult to access due to its remote location, families could visit Carville regularly.

Despite these earmarks and absence of a conspicuous hospital routine, when Parker arrived, Carville could hardly be described as a social and certainly not as a civic community. Carville was, in many respects, a place of ". . . monotony for people left together day after day, year after year. . . ."[2] Little was demanded of the patients save remaining within the facility grounds; they were required neither to attend meals nor take treatment; individual and group activities, such as baseball games or tennis matches, were left solely to the initiation of the patients. Some individuals pursued free enterprise. Others did nothing.

In addition, little cultural precedent existed for the kind of economic, racial, ethnic, and religious pluralism that prevailed at Carville. The patient population was up to 40% foreign-born—with most coming from Mexico, China, and the Philippines—and female.[2,5] Less than 10% of the patient population was black. And the patients came from diverse social and economic backgrounds and religions. Three-quarters were Catholic, and while the rest were largely Protestant, some Jewish patients always resided at Carville. Although the dorms and the dining hall were segregated when the Public Health Service (PHS) took over the facility in 1921, ". . . segregation was more or less

discouraged . . ." and Carville was integrated relatively quickly and easily.[6]

Despite the unprecedented lack of segregation, the racial, ethnic, and religious diversity that prevailed within the walls of Carville complicated community formation. In Parker's cottage of 12 women, she felt little hope for companionship, saying of her roommates: "They were mostly from farming sections in Texas, Florida, and Louisiana. We had nothing in common—no meeting ground save their curiosity."[2] The only female patient Parker's age was a Chinese girl who lived in another house. For Parker, however, it was not only social and racial separation that made integration into Carville difficult; she felt that ". . . friends, love, normal living were waiting for [her] at home. . . ."[2]

After six months in Carville, however, when she went home for a week's vacation, Parker found that she maintained both a physical and emotional distance from family and friends, despite the very remote chance that she might infect anyone. "Segregation had worked its havoc," she said.[2] Throughout the continuing years of her confinement, Parker's family always visited her, but as was the case with so many romances and marriages, her relationship with her fiancé failed to survive the first year. As her stay lengthened, Parker stated that even if she were discharged, she would always feel the "stain" of leprosy, always worry that someone might discover where she had been, always fear that the disease would return, always dread infecting others.[2] Thus, Carville came to represent a place of refuge, an asylum, from the stigma of her disease.

Whereas Parker saw Carville as a safe haven almost from the outset—a place that protected innocent people from her infection and gave her a sense of relief—others viewed it more as an escape from public scrutiny. Stanley Stein, for example, came to Carville in 1931, when he was 33. He had been diagnosed with leprosy while working as a pharmacist in San Antonio when he was 22 years old. He initially elected to receive the loathsome Chaulmoogra oil treatment from a sympathetic local physician who kept his secret. As his condition worsened and acquaintances ceased to recognize his face, Stanley moved to New York, the only state that did not require the isolation of those with leprosy (provided they did not have the open lesions that Stein would quickly develop). Ultimately, Stein's condition and fear of making appearances prompted him to go to Carville. Carville represented a means for him to escape public and family scrutiny, to avoid embarrassing questions and unnerving stares. (Unpublished data, documentary, *Secret People: The Naked Face of Leprosy in America*; 1990.)

For whatever reasons patients viewed Carville as a haven, a sanctuary, they would all come to resonate—ironically, since people were confined in Carville by force of law—with New Deal notions of freedom and citizenship that prioritized state-supported economic security.[7] Shelter, food, clothing, and medical care were guaranteed to all patients by the state, regardless of race or social class. Many patients held part-time jobs that even enabled them to buy a few luxury items. Thus, patients' perceptions of Carville in the 1930s were remarkably consistent with what would, after 1933, become prevailing notions of the universal rights of citizens as they were formulated during an era of economic crisis and state control.

The chief critique that patients at Carville leveled against one another during this period was that too much security made people lazy dependents.[7] Thus, when he arrived at Carville in 1931, Stein—who, like others at Carville, had assumed an alias to protect his family—recalled that he was ". . . not nearly as disturbed by the medical aspects of [his] new life as [he] was by the strange moral climate . . ." at Carville.[8] "It was the curious feeling of hopeless apathy I encountered everywhere that so depressed me," he said.[8] While many patients were willing to help friends, ". . . a desire to work for the common good . . ." was absent.[8] It was Stein's ". . . [interest] in the common good . . ." that inspired him to begin a weekly newspaper in order to create a sense of commonality and ". . . relieve the tedium of [the patients'] lackluster existence. . . ."[8]

With the permission of the medical officer in charge (MOC), Stein and a handful of fellow patients initiated *The Sixty-Six Star* in 1931, three months after Stein's arrival. This first iteration of the patient newspaper printed gossip, jokes, the Sunday menu, sports news, advice to the lovelorn, and the like. While it was not a radical publication, the paper began a campaign for better facilities and equipment. It was, Stein wrote, ". . . the first time in Carville history patient needs and opinions had been made known beyond the barbed wire [surrounding the hospital] without going through local official channels. . . ."[8] Parker would write, "It was not long before the *Star* had brought about a finer community spirit than had ever before existed in Carville, and the majority of patients were taking pride in their newspaper, their community, and all that was being accomplished 'inside.'"[2]

Stein was responsible not only for organization of the patient newspaper, but was also involved in establishing an American Legion Post within Carville in 1931 and 1932. The work of the American Legion during the 1930s was shaped primarily by Depression-era notions of the rights of citizenship and the bene-

fits of organization in achieving a certain minimal standard of living.[7] Thus, the Legion made few efforts during this decade to do anything other than improve the living conditions within Carville, which continued to be viewed chiefly as a sanctuary, a source of security to which the residents of Carville were entitled.

Emblematic of the ways in which larger social and political thought shaped the possibilities within Carville, *The Sixty-Six Star* died abruptly in 1933 when it became more ambitious and demanded a change in perspective that lacked cultural precedent. Stein began to use the patient newspaper to educate people about Hansen's disease, its mildly communicable nature, the unnecessary stigma attached to "lepers," and lack of grounds for compulsory confinement.[8] While the PHS did not admonish the paper for this stance, when *The Star* directly rebuked the local Catholic priest and, indeed, the Catholic Church, the largely Catholic patient body and patient staff abandoned the paper—subscriptions were cancelled, and employees and volunteers quit submitting articles and working on the publication.[8] The time had not yet come to challenge either the Catholic Church or the prevailing notion of Carville as a safe haven. That Stein would start up a new patient paper in the 1940s that would challenge both successfully underscores the extent to which the changing social and political context shaped the patients' perceptions of their rights within and the possibilities for activism at Carville.

CARVILLE AS PENITENTIARY: WORLD WAR II AND THE COMMUNITY RECOGNITION OF FREEDOM

When *The Sixty-Six Star* died, the morale among the patients sank to a new low. The paper's demise coincided with a devastating malaria epidemic that took a heavy toll among the patient population.[2] Many who did not die began to get worse. Stein himself grew increasingly infirm, lost his vision, nearly lost his life, and became despondent.

Just a year before the attack on Pearl Harbor, Dr. Guy Faget took command as MOC. Less of an administrator and more of a bench scientist than his predecessors, Faget brought Carville into a new era of therapeutic experimentation. In 1941, Faget began trials with a new class of sulfones.[2] The sulfones—first Promin and then Diasone—resulted in marked improvement in early cases within several months; and within two to three years many patients were being discharged as bacteriologically negative.[9]

Initially, in true New Deal form, patient optimism at the success brought forth expressions of gratitude for treatment. In 1941, for example, Parker—now Betty Martin following her marriage to a fellow patient—would write, "Only in America could a hospital like this be found, where we sick are treated by our government, not as the least among men, but as the best."[10] Availability of the sulfones initially heightened patients' sense of privilege rather than confinement, for Faget did not report the results of his studies for three years,[11] making Carville the only place in the world where the sulfones were available for the treatment of leprosy. With such a prevailing attitude, Dr. Faget would begin to stress the importance of patient compliance: "The greatest cooperation of the patient with his physician is most conducive to a happy outcome."[12] Thus, without imposing any hard-and-fast rules, Faget expressed a new desire to more closely regiment the sleep patterns, meal consumption, recreation, and other activities of patients—all toward the end of arresting their disease in "the modern leprosarium."[13]

While the sulfones initially heightened the patient's sense of privilege—of reaping the benefits of a welfare state that provided for the needs of the most vulnerable—they also instilled a new sense of autonomy and a new willingness to challenge and critique. Thus, while the penal characteristics of Carville had never been lost on arriving patients,[8] it was not until they felt better and began to think about the possibility of discharge that patients began to resent that they were ". . . still being treated very much like inmates of a penal institution. . . ."[8]

But technological triumph alone is not sufficient to explain the new patient emphasis on the penal aspects of Carville after 1941. Residents had long been denied conveniences, services, and rights at Carville during the 1930s. But while conditions at Carville had not changed, the status quo became entirely inconsistent with the new rhetoric of freedom that infused American efforts during World War II.[7,8] Beginning in 1942, President Roosevelt began to promote attention to fundamental civil rights as the nation increasingly embraced the notion of a pluralistic society.[7] The changing atmosphere helped to inspire not only the civil rights movement, as racial segregation and discrimination became increasingly difficult to justify in a nation battling Nazi tyranny and racism,[7] but also ended tolerance for the long-prevailing conditions at Carville.

The institution's residents lacked the vote. There was no post office on the facility grounds. Patients could send and receive mail only if a staff member volunteered to deliver it—after it was sterilized sometimes to the point of charring. Likewise, patients had no access to a telephone. If patients needed to make an emergency phone call, they had to slip through a

hole in the barbed wire fence and hire an expensive taxi to take them to Baton Rouge and back—all at the risk of being caught and punished. While short vacations were permitted to 10 patients at any one time—a source of heartbreak at Christmas—they could travel only with the permission of the state health officers at their destinations and had to avoid all public transportation.[14] Moreover, only patients from Texas, Louisiana, and Mississippi could travel home at all.[8] Also, an informal prohibition on patient marriages denied couples the right to live together unless they had the resources to build, rent, or buy one of the officially unauthorized but tolerated shacks or cottages that patients built toward the back of the hospital grounds.[8]

It was in this climate, in 1941, that Stein resurrected the patient newspaper as *The Star*. While it continued to contain advice, gossip, sports, humor columns, and a ladies' section giving advice on hem lengths and room decoration, the chief goal of *The Star* was to educate the public about the nature of Hansen's disease and eliminate use of the words "leper" and "leprosy" as a means of undercutting public support for isolation.[15] The motto of the new publication—*Radiating the Light of Truth on Hansen's Disease*—reflected its expanded mission.[16]

The Star became the primary organ for demanding changes within Carville. Although initial demands were relatively uncomplicated—the first was for a paved road from Baton Rouge to the hospital to minimize isolation—by the winter of 1942, Faget felt threatened by the increase in patient confidence and authority and warned new patients against "old-timers," who ". . . feel [they] know as much about [their] condition as the doctor does. . . ."[17] As a reminder of exactly who was in charge at Carville, Faget published the 11 official PHS Rules and Regulations in the April 1943 issue of *The Star,* noting that they were still in effect and that patients should start familiarizing themselves with them.

Although Faget did not directly threaten to enforce the rules, the patients saw little value in them and immediately began demanding their revision and revocation. In a new social and political context, Faget's reminder about the rules helped patients to develop a sense of their common welfare—a critical step toward a vision of themselves as more than just a group of people with connections and obligations to one another, but a group with the same fundamental political, social, and economic rights and entitlements enjoyed by the larger American community.

While every rule prompted criticism, the sharpest attacks were leveled against the prohibitions against fraternization of the sexes (and the unwritten but enforced rule against patient marriages on the grounds of Carville) and compulsory isolation (the rule that stated patients must not proceed beyond the limits of "the reservation" provided for their detention).[18] From the subtle imagery of dictatorships and Reichs in *The Star*, Carville patients understood that rules, without official revision, could ". . . be twisted to meet the particular whims of the MOC who may be in charge. . . ."[19] Stein wrote, "It is high time that the authorities realize the folly of treating Hansen's disease as if it were a crime instead of an illness."[20] So as information and propaganda regarding Japanese prison camps and Nazi concentration camps began to accumulate in the 1940s,[21] Carville patients became more outspoken regarding compulsory isolation, using stories of veterans sent to Carville to drive home the injustice. In addition, the patients began demanding not only the revocation of the rule regarding visiting between the sexes but that Carville provide official housing for married couples. The goal was ". . . to get the 'institution' out of . . ." Carville. As one patient explained to the MOC, the infirmary ". . . is the hospital but out there (pointing to the patients' cottages) is our home. . . .'"[22]

Such emphasis fostered the question among the Carville patient population: "What Have we Here—Hospital or Penitentiary?"[23] The language and intent of the regulations made clear to patients that while the PHS might, indeed, hold that ". . . to contract leprosy is not a crime," the regulations did in fact make living with this feebly communicable disease outside the confines of Carville "a crime against society."[24]

By 1946, Faget was on the defensive. Patients had challenged not only the medical profession but also, most ungratefully, the hospital itself. Thus, he began to maintain that patients ". . . should consider their admission a privilege. There is no charge for treatment or for hospitalization. The first thing they will find out is that the patients live here with all the comforts of a first-class hotel. This is not an asylum but a hospital. The patients are treated as sick people."[25] Treatment of the sick, however, was also becoming an issue as patients, in the aftermath of the newly promulgated Nuremberg code regarding medical research abuses, resented the notion of being treated as research fodder. Thus, in an atmosphere where patients increasingly resented not being fully informed about the nature and risks of experimental treatments, they began to regard unquestioning cooperation in their treatment as an act of submission.[26]

The patients not only lodged their protests in *The Star*, but also began to advocate for a formal recognition of their rights with federal officials and politicians—an effort that would take a concerted effort on

the part of patients who organized the United Patients' Committee for Social Improvement and Rehabilitation. The United Patients' Committee included *Star* staff and other representatives from the patient body, including, critically, members of the American Legion post, who would use the influence of the national organization to help make the claims public.[8] The committee made 15 recommendations that sought not only to overturn unacceptable rules, but also to abolish the practice of compulsory confinement and establish the treatment of Hansen's disease through a proposed series of outpatient clinics.[8]

The emphasis on outpatient treatment was part of a larger movement toward deinstitutionalization and community care that began to gather steam in the 1950s, becoming full-blown in the 1960s and 1970s. It was influenced by many of the same factors that began to erode the notion that institutionalization was most appropriate for the treatment of the mentally ill. Those factors included post–World War II successes with early intervention and treatment in community outpatient clinics, a decline in the Depression-era certainty that the state was responsible for social welfare and security, public exposés on the weaknesses of institutional care, and successful new therapies.[27]

In 1946, a new National Advisory Committee on Leprosy, appointed by the Surgeon General at the suggestion of the American Legion, met to begin considering the recommendations of Carville's United Patients' Committee.[28] The Advisory Committee included representatives from the American Legion, the lay community, the medical community, and the National Institutes of Health and PHS.[8] After their second and final meeting, radical changes in Carville policy took place.[29] They were in part made possible by Faget's retirement in 1947, based on his declining health, and his replacement with Dr. Frederick Johansen, a long-beloved Carville physician, as MOC.[30]

Almost immediately, Johansen began fostering a community atmosphere. Under his administration, the road to Carville was paved and the barbed wire atop the fence surrounding the facility was removed.[31,32] Johansen also implemented key recommendations of the National Advisory Committee: patients were granted a one-month leave twice a year with transportation provided by the PHS; a post office branch was established at the hospital (although the requirement that all outgoing mail be sterilized remained despite intentions on the part of the MOC to abolish it); and patients were offered medical discharges while still in the communicable stage of disease provided they could arrange for adequate treatment at home.[8] With a restored sense of autonomy, patients abruptly ceased complaints about being involuntary research subjects and once again emphasized that the choices they made were their own.[33]

CARVILLE AS COMMUNITY UNDER SIEGE: THE COLD WAR YEARS

The benevolent response to patients, however, was akin to the separate but equal approach to blacks during this time and did not yet represent official PHS regulation. Johansen found himself continually defending his liberalization of the patient leave policy against those within the PHS who continued to maintain that leprosy was highly contagious and required the strictest isolation. Thus, in the wake of these sweeping changes, an effort began within the PHS to discredit Stein and *The Star*.

In 1949, *The Star* published an editorial accusing the PHS of violating the patients' right to privacy by requiring patients to consult with physicians from within the waiting room across a chain and allowing press representatives into the clinics without informing patients that they were being interviewed by journalists rather than doctors.[8] These complaints, coming just at the start of the U.S. Cold War effort to contain Soviet power and stifle internal domestic dissent, touched off an official PHS investigation of the patient publication. An investigator—who had apparently furtively served on *The Star* staff for several days—concluded in a report that Stein was not credible and neither was the publication. His report charged that while *The Star* purported to represent the patient body, "The rank [of] patients feel that *The Star* neither reflects Carville nor represents the patients." The report therefore recommended that the paper be gradually reduced to a quarterly with no ". . . stories and allusions to friction between the patients and staff, the patients and the Public Health Service. . . ." (Unpublished data, anonymous report, *The Star*, PHS Records, National Library of Medicine, Bethesda MD; post-1946.) In short, the paper could exist, but further dissent must be effectively stifled.

Stein and *The Star* had their firm supporters within the PHS, however, and none was stauncher than the current MOC. Johansen, as a federal official no doubt attuned to the devastating potential of personal investigations to destroy careers in government during this McCarthy era, unflaggingly defended Stein and *The Star* as representative of the larger patient body. But *The Star* investigation, while consistent with the larger culture of intimidation, was a minor incident mirrored by relatively minor complaints during a period in which the patients enjoyed the broad support of a benevo-

lent MOC. The patients, however, had been prescient about the effect that the whims of any given MOC could have on life at the institution when they first challenged the PHS rules and regulations in 1943. Patients might have the power and influence necessary to organize national advisory committees, they might have very satisfying recommendations regarding the treatment of Hansen's disease in hand, they may have fostered an unprecedented sense of community within Carville's walls, but without definitive changes in rules and regulations, they remained vulnerable.

In 1953, Johansen turned 65—the mandatory retirement age. He was replaced by Dr. Edward M. Gordon, who, reminiscent of the Communist purges taking place at this time, immediately declared that all able-bodied arrested cases must leave the institution; he invited the partially and permanently disabled to leave, as well. Many of these individuals had been at Carville for a decade or longer and often had not maintained contact with their families. For others, their ". . . lives had become 'institutionalized. . . .'"[8]

Even those who did not face mandatory discharge found themselves threatened within Carville: Many were let go from their part-time hospital-based jobs and replaced by civil servants or locals; husbands and wives were prevented from both holding jobs.[34] These individuals were not deemed threatening or insubordinate in any way; it was, rather, the notion of patients participating in their own medical care and general supervision that was challenging to PHS medical authority under Gordon.

The mandates regarding discharges and employment were accompanied by a host of other changes that the patients found objectionable. For example, Gordon, while not abolishing outside visitors, restricted visiting hours and allowed only guided tours; he also "advised" hospital staff and officers to cease fraternizing with patients. Gordon justified both measures on the grounds that, because leprosy was a contagious disease, ". . . patients should have as few [close, intimate] contacts with non-patients as possible. . . ."[35]

In response to the changes wrought by the Gordon administration, the patients did not use *The Star* as an outlet for direct activism. Although the paper had already survived one investigation, the nation was more firmly locked in an anti-Communist crusade by 1953. While there were no indications that patient dissent would be associated with Communism, patients were particularly vulnerable. In part, the dictum regarding mandatory and voluntary discharges put the patients at greater risk, so they had to weigh carefully whether and how to rock the boat. Although *The Star* did highlight stories featuring patients' fears regarding leaving and their abandonment by families—an indirect criticism of the mandatory discharge policy—it did not directly confront the local administration as it had done in the past (until official announcement of Gordon's departure in 1956). Despite this change, the PHS renewed investigations of the publication.

Stein was also personally constrained under Gordon, which affected *The Star's* ability to serve as an outlet for pointed patient protests. Although he was blind and thus not at risk of being forced out of Carville, his private cottage was at stake. Gordon had determined that the patient-constructed facilities were government property—a matter of much concern among the patients, for these cottages represented not only normality but also financial security. Patients had either paid for the cottages to be built or purchased them from the original builders. Further, they had added light, heat, and all equipment and furnishings at their own expense. The cottages represented the patients' primary if not sole investment. If Stein were to lose his cottage, he would have to give up the convenience of paying a patient orderly to assist him, and live instead in one of the dormitories for the blind, where a dozen or more blind patients were cared for by a single attendant.

Carville patients thus relied on the Patients' Federation—a representative, elected body of the patient population that handled patient funds and served as the patients' political voice. The Federation chose to protest primarily through the Baton Rouge press and elected officials. Building on growing national efforts to end public housing projects—depicted as "socialized housing"—and a surging sentiment that one's home represented "the center of freedom,"[7] patients made the all-American issue of housing their cause, rather than potentially inflammatory claims regarding civil liberties.

Although U.S. Congressional Representative Emanuel Celler introduced legislation that ultimately resulted in a House appropriation of $25,000 to compensate patients for the housing,[36,37] the PHS continued to threaten the sense of family, normality, security and, hence, citizenship that the cottages represented. After promising to renovate the existing cottages, the PHS suddenly determined that they must be razed and replaced with new apartment quarters for married couples only. In the new apartments, patients would no longer be allowed to cook in their rooms, but would instead be required to eat in the cafeteria with the rest of the patients. Gordon reasoned that women should not mind being relieved of the burden of cooking and, indeed, reportedly shouted, "For some strange

reason you think because you are married, you have to live in a private cottage and have your meals there. You married since you came here. You didn't come here married. Why do you think you have to have separate cottages and food apart from the other patients?"[38] Gordon did not recognize the patient body as more than an assemblage of unaffiliated patients and justified the changes as being merely good hospital administration aimed at "protecting the public health."[39]

Darryl Broussard, President of the Patients' Federation, declared that the situation had ". . . reached the point . . . where the patients have no confidence in or respect for the MOC. . . ." The Patients' Federation campaigned actively for Gordon's removal from Carville.[39] In protest, the Federation cancelled all community activities. Although this was likely to be lost on an administration that did not recognize the patients as a community, the refusal to participate in the community was a bold move on the part of patients, equivalent to a sit-down. Broussard said, "The cancellations will continue until they give us back what they took away from us."[40]

In August 1956, the Federation retained a lawyer and contacted their Congressman, Otto E. Passman, who came to assess the situation for himself. Passman, a member of the House Appropriations Committee and the first U.S. Congressman to visit Carville, sided with the patients, whom he regarded as citizens, taxpayers, and voters deserving of the same rights and having the same legitimate desires as any of his constituents.[41] Shortly after Passman returned to Washington, D.C., Gordon requested and was granted a transfer.

CARVILLE AS HOSPITAL: THE DUSK OF COMMUNITY

The new MOC, Dr. Edgar Bernard Johnwick, was installed in November 1956. He immediately did the unprecedented and called a general meeting of staff, medical officers—and patients. Carville's goals, he explained, would only be accomplished if undertaken by "a team that is made up of the staff and patients."[42] Johnwick made clear that the policies of the Gordon administration would not stand: "No one should be discharged from this hospital against his will. No one should be kept in this hospital against his will."[42] While this attitude was very favorably received by patients, it is significant that Johnwick saw the patients as partners in their cure, not primarily as community members, though he certainly did not oppose any community-building efforts. The irony was that at the height of their victory and the peak of their sense of themselves as a true community, the Carville community began to collapse as more and more patients—both long-time and newly admitted cases—accepted medical discharge as effective drug regimes were developed.[43,44]

The Star mirrored the profound changes at Carville. The new Johnwick administration viewed *The Star* with both respect and sympathy and made concerted efforts to save the publication after Stein's health began to decline and the patient population became less permanent.[45] In 1956, the paper was forced to begin publishing only every other month.[46] Johnwick found the long-term solution to be for the PHS to take over operation of the paper, continue to employ patients, and continue to give them a share of the paper.

Although the paper would remain in Stein's hands up until his death in 1967, the nature of the publication radically, and appropriately, changed. By the 1960s, *The Star* calculated achievements and needs in terms of treatment, research, staffing, and facilities improvements rather than community advancement; the activities of the PHS within Carville tended to dominate the paper while the patients concentrated almost exclusively on the campaign to dispel the myths of leprosy, the need for vocational rehabilitation to facilitate patient discharge, and finally the need for pensions to enable long-time patients who would have difficulties finding employment to return to "their families and communities."[47,48] Indeed, in 1965, *The Star* staff explained that, "Many persons still think of *The Star* as an organized protest of patients against the hospital administration. More recently however, our mission has been to educate professional people and laymen alike to the facts about Hansen's disease."[49]

Certainly some patients admitted to Carville after the 1940s spent up to 10 years in the institution,[8] but the patient who began to respond to treatment within a few months and who could then expect to be discharged from Carville within two or three years tended to view the facility much differently than did the individual confined for decades. Carville also became even less of a closed institution. By 1959, Carville adopted a liberal pass policy and allowed patients to own their own cars and use them for shopping or recreational trips in the surrounding area. The cars also made it easier for patients to go on employment interviews and otherwise prepare for discharge.[50] The new generation of patients had little reason to be concerned with individual rights and community welfare within Carville.

This new generation of patients, however, did take up the charge to promote knowledge about Hansen's disease after discharge. Gertrude Hornbostle, a patient at Carville from 1946 to 1949, and her husband, Major

Hans Hornbostle, were the first to speak out against the confinement of those with Hansen's disease and educate the public in an effort to reduce its stigma.[51,52] Signifying a new kind of pride and celebration of identity and survival that would become part of the public experience of breast cancer, AIDS, multiple sclerosis, heart disease, and a variety of other chronic diseases or disabilities in the decades to follow,[53] the Hornbostles were the first of the new generation to retain their true names within Carville.[54] The positive reception that they received from the press and the public emboldened others to begin speaking about their experiences and the disease at social gatherings, churches, and service clubs and organizations.

But such public ownership of leprosy was something that those who had lived for decades within Carville were often not up to. Although Betty (Parker) Martin would become internationally known with the success of her autobiography, she had ". . . suffered too long in loneliness and fear . . ." to risk becoming a public figure.[55] She understood that her one true community had been lost forever, for Carville as a community with culturally-bound values and expectations existed only in the unique historical moments of the 1940s and 1950s. Thus, after years of freedom, Martin would continue to feel unease with those on the outside, conceal her identity, and maintain the stance she took in 1959 as the community dissipated: "We belong with the secret people."[55]

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