Rancho Los Amigos Post-Polio Support Group

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This article provides insights into the feelings of many of us about the equipment we used during acute polio, rehabilitation, and coping with post-polio. I think you will enjoy reading these personal perspectives. Perhaps you will be reminded of how you felt many years ago, and how you might feel today facing some of the same issues. See if you can relate to any of these feelings. If you used braces, crutches, a wheelchair, or an iron lung, did you feel stigmatized as a cripple? Do you react differently today? We would like to hear about your experiences, and how you coped then and are coping today.

Braces, Wheelchairs, and Iron Lungs:
The Paralyzed Body and the Machinery of Rehabilitation in the Polio Epidemics

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Recalling the polio epidemics of the 1940s and 1950s conjures up iconic images of March of Dimes poster children encased in heavy steel and leather braces, boys and girls confined to wheelchairs, and a few unfortunates condemned to iron

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lungs in order to breathe. The pitch of these posters was that by giving your dimes and dollars to the National Foundation for Infantile Paralysis you could help a child shed his braces, park her wheelchair permanently, or leave an iron lung, able to breathe on his own. Fears of crippling induced Americans to part with millions of dimes to cure polio and to aid those already stricken. Unlike most contributors to the March of Dimes, polio patients and survivors often had a conflicted response to this machinery that kept them alive or that provided mobility. They shared with other Americans the cultural dread of braces, wheelchairs, and iron lungs as emblems of paralysis and incapacity. But as many discovered in hospitals and rehabilitation facilities, these assistive devices had a positive function they came to appreciate. Getting braces meant that you would soon leave the rehabilitation hospital for home. Getting a wheelchair meant that you were mobile once again. And an iron lung kept you alive to enjoy family and friends. Reaction to these assistive devices was and is culturally constructed and polio survivors had to shed their fear of these devices and embrace this technology in some fashion if they were to lead useful lives.

Fear of crippling was pervasive during the polio epidemics of the mid-twentieth century and this fear was reinforced by the myriad images produced by the March of Dimes to raise funds for the National Foundation for Infantile Paralysis. Poster children were chosen locally and nationally to represent polio’s power to cripple and to induce Americans to give generously so that they and their children could escape the virus. Paul Longmore[1] has pointed out that these kinds of images of disabled children embody what “Americans individually and collectively fear most: limitation and dependence, failure and incapacity, loss of control, loss of autonomy, at its deepest level, confinement within the human condition, subjection to fate.” Most of these young poster children were, of course, photogenic, but they were also pictured wearing their braces, using crutches, or rising out of a wheelchair. As Jane Smith[2] has observed, “cute little kids on crutches, kids from your home town, were what opened wallets and the coin purses.” In addition, the March of Dimes arranged newspaper photographs of local children who had been helped by the National Foundation for Infantile Paralysis, of iron lungs being donated by companies or service organizations and of crippled children attending special summer camps. Newsreels of the time had dramatic images of polio patients struggling to walk, typing with a mouth stick, or lying immobile in an iron lung watching the world through a tilted mirror.[3] The public relations and fund-raising campaigns of the March of Dimes provided constant reminders in the

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forties and fifties of polio's potential to cripple and imprison youngsters and young adults in braces, wheelchairs, and iron lungs. In addition to these powerful media images, the prevalence of polio in these years meant that many Americans knew someone who walked with braces and crutches or who used a wheelchair. If not exactly commonplace, these individuals nonetheless made an impression on all who saw them. As the writer Annie Dillard[4] recalls in her memoir of an American childhood, "We had all been caught up in the polio epidemic:…the girl in the iron lung reading her schoolbook in an elaborate series of mirrors while a volunteer waited to turn the page; my friend who limped, my friend who rolled everywhere in a wheelchair, my friend whose arm hung down, Mother's friend who walked with crutches."

The extensive efforts of the March of Dimes and the National Foundation for Infantile Paralysis to raise funds for research and care and to heighten the public awareness of the disease helped create a popular image of the polio victim as a dependent cripple. What Americans tended to remember from the poster images, the photographs in *Life* and *Look* magazines, and the newsreels at the movies were the ugly cumbersome braces, the confinement to a wheelchair, or the horror of being imprisoned in an iron lung. These potent images overrode any other messages about the capabilities of polio survivors. Many polio survivors remember that in the awful early days of their sickness their fears and anxieties were heightened by these ubiquitous images of crippled children. Edward LeComte[5], who had polio as an adult, recalled that polio was a "well-advertised disease, better known than other afflictions that are as bad or worse." What stuck in his mind were the images of "the little wasted limbs, the pathetic crutches." Jim Marugg,[6] another adult victim of polio, remembered that before he developed the disease his "idea of polio was gathered mostly from March of Dimes posters, pictures of children wearing braces." When Peg Kehret's[7] father told her that she had polio, she panicked and started to cry. She immediately remembered "*Life* magazine pictures of polio patients in wheelchairs or wearing heavy iron braces." She recalls that "the posters hung in stores, schools, and libraries—frequent reminders of the terrible and lasting effects of polio." When told that his wife had polio, James Liston's[8] first reaction was "*that's infantile paralysis: that's what those crippled kids have…paralysis.* And a picture from a March of Dimes poster, a youngster in heavy leg braces, flashed through my mind." Charlene Pugleasa[8] was thirteen when she learned she had polio. The first thing she thought of was "all those miles of film footage" she had seen at the movies. It seemed as if the

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newsreels that preceded the feature always had something about polio and “it kept everybody very afraid.” She conjured up “pictures of just rows upon rows of kids in wards in various stages of deformity and paralysis. Some in iron lungs.” And she worried whether she was “going to become this horribly crippled person.” Like Pugleasa, Regina Woods[10] remembered the “March of Dimes programs” once the doctor diagnosed her polio. Her conception of the disease was that “everyone who had polio went to the hospital, got a brace on one leg, and went home, often leaving the hospital as Howard Keel sang ‘You’ll Never Walk Alone.’” The efforts of the NFIP to reassure parents and others that most polio patients recovered, that polio could be overcome, and that help was available was pushed out of mind when polio was diagnosed. What remained were the frightening images of crippling and the mechanical devices used to compensate for what polio had destroyed.

Some polio survivors have recalled that before their own encounter with the virus they had little sympathy with polio victims or with other individuals with disabilities. Hugh Gallagher[11], for example, “did not like the disabled.” In fact, he “was afraid of them.” While growing up in the thirties and forties he encountered “a general, perhaps unconsciously felt, fear of the disabled. This was not so much a fear of *them* but a fear of what they symbolized—human vulnerability to disease, disability, and death.” Gallagher’s feelings were so strong that he remembers crossing the street rather than “pass by a severely handicapped person.” On another occasion he again crossed the street, this time to avoid passing an iron lung on display outside a theater to raise funds of the March of Dimes. Hugh Gallagher’s reaction may have been extreme, but it was certainly not unusual in the decades when the polio epidemics were at their height. As Fred Davis[12] observed in his study of the impact of polio on families, by the post-war era polio “had emerged in popular thought as more than a sometimes crippling disease of children; it was regarded as a powerful symbol of blind, devastating, and uncontrollable misfortune.” Before they contracted polio, these victims of the virus shared the widespread cultural attitudes toward the disease and disabled individuals. Once diagnosed, they had to wrestle not only with the painful disease and a difficult and protracted recovery, they also had to come to terms with their own preconceptions, especially when polio left them dependent on iron lungs, braces, and wheelchairs.

Given the prevalence of these mechanical devices as symbols of polio and

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disability, it is not surprising that most if not all polio patients had very conflicted emotions about iron lungs, braces and wheelchairs. To assent to using them was a certain sign that one had left the world of the able-bodied and crossed over to the world of the crippled, the handicapped, and the disabled. Using these devices meant that your body had failed you. Things you took for granted—breathing, walking—now became slow and laborious. You would be dependent on machines to breathe and to get from one place to another. You had become that pathetic child in braces, that young man confined to a wheelchair, the young woman imprisoned in her iron lung. The natural inclination was to resist dependence on these mechanical devices, but the paralyzed body often gave you no choice. If you wanted to breathe, to live, the iron lung was a necessity. If you wanted to get out of bed, to be mobile, braces or a wheelchair offered the only options. Many polio patients eventually embraced their mechanical aids as "friends" that in some sense had restored them to life. In the case of the iron lung, restored them to life quite literally when they were in danger of dying, and in the case of braces and wheelchairs restored them to life outside the hospital, outside the home, on the playground, in the schools and at work.

Braces, wheelchairs, and iron lungs were used in very different stages of polio. Braces and wheelchairs were typically used following the acute stage during the long recovery and rehabilitation. However, if an iron lung was necessary, that happened very early in the acute stage of the disease, sometimes within hours of being admitted to the hospital. If the creeping paralysis reached the intercostal muscles that controlled breathing, the need for respiratory assistance could develop very quickly. Giving oxygen was not sufficient, for with paralyzed muscles there was no ability to pull the oxygen into the lungs and to expel the carbon dioxide. Before the development of the iron lung in 1928 by Philip Drinker and his associates at Harvard doctors had no way to keep such individuals alive. From almost the beginning of the development of this technology, the iron lung, as David Rothman[13] has pointed out, inspired both admiration and horror. Early polio cases that successfully employed the iron lung, particularly the widely publicized case of Frederick Snite who contracted polio in 1936 in Beijing and was placed in the only iron lung in China, seemed examples of how modern medical technology could bring patients back from the brink of death. But Rothman notes that there developed at the same time "a no less acute sense of dread and revulsion about the personal ordeal that such treatment imposed." In addition to descriptions of the iron lung that suggested "strength, durability, and

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awesome power" there were "darker images of a casket, a prison cell, a sense of entrapment and entombment."

David Rothman's study of the development and use of the iron lung in the polio epidemics sweeping the country in the thirties, forties and fifties reveals the problems that emerged as the machines became more widely available and more frequently used. They were generally quite reliable mechanically, but in spite of some dramatic instances of lives saved, doctors had some serious concerns about the tank respirator. Rothman cites a 1941 study by Dr. James Wilson, a pediatrician and polio expert, who examined the use of iron lungs for the NFIP. Wilson suggested that more than half the cases involved individuals with bulbar polio, for whom the iron lung was not an effective treatment. He was also concerned that as many as one fourth of those who could benefit from the machine were placed in it too late. Wilson speculated that some of the delay could be attributed to "the frightening appearance and the disturbance…[this] big, coffin-like apparatus… causes in a hospital." Wilson also worried about the quality of life of the patients whose lives the lung saved. In spite of his reservations, Wilson, who along with other physicians "shared an unremittingly negative view of life with a disability," was "unwilling to allow the technology to remain in short supply." The NFIP soon put in place a program to purchase a significant number of iron lungs and distribute them around the country so that they would be available in the inevitable polio epidemics. Regardless of their reservations, when "confronting a dying patient, doctors would do something, almost anything rather than just stand there, or even give comfort. Although they might later regret having preserved a life that was to be spent confined within a tomb, they acted no differently the next crisis round."

In spite of the efforts of the National Foundation to portray the iron lung as a modern medical miracle, the prospect of being placed in one was daunting. As they struggled to breathe with their increasingly paralyzed muscles, most polio patients looked with dread at the large yellow tanks parked in the hall outside their rooms, hoping that it was for somebody else and that they would avoid being placed in the large can. For example, Linda Atkins[14] remembers her fears in the isolation ward of Boston Children's Hospital listening to the "slow, steady *whoosh* of the pale green iron-lung tubes" on the other side of the room. The constant whoosh of the respirators even invaded the "deep, dark realm of her dreams." As she looked across the room at the patients in the iron lungs, she feared that she "was about to be buried alive. At any moment, the aides in their blue sanitary suits

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… would take me and slide me into one of those hungry, disease-breathing green monsters.” Atkins was fortunate in that she never needed to be slid into one of the long green tubes. Others who feared the big green or yellow machines were not so lucky. As Larry Alexander’s[15] ability to breathe failed in spite of the oxygen he was receiving, he remembered the “monstrous iron lungs out in the corridor, only now they weren’t monstrous. They were angels of salvation.” Others, particularly polio survivors who had been children when paralysis robbed them of the ability to breathe recall being bewildered at how one got into the big machines. Their anxiety was only heightened by the failure of doctors and nurses to explain what was about to happen. Marie Latta[16] still has a “horrible memory” of being “stuck into that big green tank.” No one explained the procedure to her and when she saw “that monstrous machine” she thought they were going put her in it “head and all.” Her relief when “they did not close [her] head in was beyond description.” Regina Woods had been on a chest respirator for four days when doctors decided her breathing needed the greater support provided by an iron lung. When they rolled one into her room she discovered “what the yellow thing on canisters had been.” She had been puzzled by the machine because “there no apparent way to get into it.” She was amazed when “the cylinder had rolled open and it had not been necessary to stuff [her] through the small opening in the end.” Facing a respiratory crisis in their patients, doctors and nurses undoubtedly had more pressing concerns than to explain what was about to happen and how the lung functioned. Explanations could come later, but not knowing what was happening made the experience especially harrowing for those about to be slid into the big yellow or green machines.

If polio patients feared the iron lungs before they were encased in the tank, they almost all remember how good it felt once the machine was turned on and its rhythm properly regulated. Typically, they had been struggling to breathe for hours, sometimes for days, before the lung was used. Regina Woods remembers that as her breathing became “labored” she was “surrounded by strangers” who kept telling her “to ‘try’” to breathe. She “didn’t understand, because nothing moved and [she] didn’t know how to *try* to breathe. [She] had always just done it.” Once doctors decided to put her in the iron lung, the process went quickly. Soon she was “in the huge cylinder with only [her] head sticking out.” When it was closed, she “was no longer struggling to breathe and the whole thing seemed wonderful.” The night that followed was one of “sheer comfort.” Allen Lee[17] recalls “fighting for breath” and “gasping irregularly.” He thought then that his

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"struggle for air could go on only for a matter of moments." Once Lee was in the lung he "was no longer fighting for air." He "relaxed" and was not "frightened" or "gasping." He now "rested in the arms of a new found friend." Before they put him in an iron lung, Hugh Gallagher complained to the nurses that the oxygen tank, which a day earlier had produced "a blessed…relief" now "seemed to be running out" as he no longer received "refreshment or sustenance from the air within the oxygen tent." While nurses assured him the tank was full and working he lay in his bed "concentrating on each breath. Each breath became conscious decision, an exhausting labor, less and less satisfying, ever more tiring." Gallagher had an emergency tracheotomy performed without anesthesia just before being put in the tank. His last memory is of "being laid out on the pallet and inserted into the tin can of the iron lung." He then passed out from lack of oxygen, the "machine was turned on, and the machine revived" him. Like Gallagher, Larry Alexander was on oxygen before being put into the iron lung. He remembers "gasping" and realizing that his "chest muscles were failing." He couldn't "force them to suck in enough air, and gradually the blackness began to creep in again, blackness and a tearing pain in his chest." Like Gallagher, doctors waited almost too long before putting him in the lung. As his breathing failed, Alexander thought of the "clean, metal lines, …pipes and gauges" of the lungs with "an almost hungry yearning." By the time the orderlies put him on the bed and slid him into respirator he was "trembling." The lung closed, "the pressure was adjusted and the pumps set to work." As he took his first breaths inside the lung, the staff adjusted the dials and suddenly the "unbearable weight on [his] chest…lifted, as if death itself were lifting from [his] body and [his] soul." The machine that only a little while before had seemed so terrifying had been their salvation. Although most survivors who needed an iron lung remember how good it felt when the lung began to breathe for them, their feelings about the lung would vacillate widely before they escaped it permanently or found themselves dependent on it for months, perhaps years.

While their initial reaction to being placed in the iron lung was a tremendous sense of relief that they could breathe once again, even if it was the machine that was doing all the work, these polio patients had love-hate relationship with the machine. With oxygen again filling their lungs, these patients revived and as they did they were forced to consider their new circumstances. They were, in most cases, completely paralyzed and dependent upon machines or other humans to manage all their bodily needs. Their visual world had shrunk to what they could

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see backwards in the tilted mirror above their heads. Not surprisingly, many thought of themselves as imprisoned in the tanks. As Hugh Gallagher put it when the machine revived him, “I regained consciousness, a prisoner of the machine.” He later compared his situation to that of Gregor Samsa in Franz Kafka’s *Metamorphosis* who “wakes up to find himself encased in the body of a cock-roach,” except that the exoskeleton in Gallagher’s case was the iron lung. Louis Sternburg[18] declared that living in the iron lung “was a life of unrelenting agony.” As far as he was concerned, “the tank was hell, but at least it was safe.” When Kenneth Kingery[19] awoke in the iron lung he saw before him only “a rounded yellow cliff” and a nameplate with the “stark words: Emerson Respirator.” He thought it must all be a “grotesque joke” or a “bad dream.” The reality was too awful to take in all at once.

One of the first things these new iron lung patients had to learn was that they had to work with the machine if they were to find any comfort in the tank. They quickly discovered that the machine dictated when and how deeply they breathed and when they could talk or eat. They also learned that they were dependent on the doctors and particularly the nurses who controlled the machine[20]. As Larry Alexander recalled, the “iron lung had covered [him] with a protective shell,” but “within that shell it had set up a rigid and systematic environment.” Since he no longer controlled his own breathing, he had to learn “to pace it to the rhythm of the machine,” which had become his “benevolent tyrant.” Like all iron lung patients, he quickly discovered that he could talk only when the lung forced him to exhale. Eating, drinking, and swallowing all had to be “synchronized to the rhythm of [his] new master.” In time, “the metal respirator assumed an almost animate personality and became a symbol of protection and security.” Soon, Alexander “clung to the respirator and refused to think of doing without it.” Like Alexander, Hugh Gallagher quickly discovered that the lung dictated how he breathed. He had to “breathe *with* the respirator.” Adjusting to the forced rhythm of the machine could be “frightening: inhale when the machine says exhale, and the result is confusion, mixed with an impotent fear.” But when he learned not to fight the machine, Gallagher acknowledged that “being in an iron lung becomes oddly comforting. It is warm, life-sustaining; its steel body protects you from the dangers of living, of breathing. It is a big womb, and overprotective mommy.” Arnold Beisser[21] remembers that the iron lung became “a vital organ.” It was now his “most personal and vital space boundary,” and served as his “new skin.” His body and its most private functions were no longer under his control. They

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belonged to the machine and its human attendants who in caring for his "body did things when and how they believed they should be done," with little apparent regard for his feelings and desires. As Beisser puts it, "they were more the owners of what lay inside the tank" than he was. Although these patients soon found a level of comfort in the machine, they were not allowed to enjoy that comfort for very long. Within a few days or weeks of being placed in the machine doctors began the painful process of trying to wean them from their dependence on the respirator.

The respirator-dependent patients' fears about leaving the iron lung rivaled the initial fear of being put in the machine. Medical practice at the time dictated that physicians begin "weaning" patients from their dependence on the lung as soon as possible. They did not want any remaining chest muscle function to atrophy while the machine did the work. Doctors also wanted to exercise and strengthen any functioning muscles so that the patients could learn to breathe on their own as soon as possible. Larry Alexander recalled that when the respirator was opened and he was slid out of it "there was always the same sinking feeling, the desperate struggle for air, and the building up of an unreasoning, overpowering fear." When doctors proposed taking Jim Marugg out of the iron lung he realized how "attached to the iron lung" he had become: "The thought of actually breathing without a ka-thump-a to help me threw me into a panic." To his dismay, Kenneth Kingery discovered that when nurses opened the lung briefly to care for him he "had to *work* to breathe." He compared opening the tank to "switching off [his] life; like dropping a piano to crush [his] chest." These brief periods outside the machine were calculated to strengthen his chest muscles and to give him confidence that he could once again breathe on his own. But as he admitted, "whatever confidence I gained from these fish-out-of-water torture trials came *after* each tank opening. Never before." Most, though by no means all, iron lung patients eventually made a transition to breathing on their own or if there was no recovery of their chest muscles to chest respirators, rocking beds, or other forms of assisted respiration. But it was almost always a difficult and painful process attended by the ever-present fear of suffocation.

Iron lung patients, then, went almost a full circle in their feelings about the machine that so dominated their lives. Once their breathing had become significantly impaired, their initial dread of the big yellow and green tanks sitting ominously in the hall awaiting new prisoners quickly gave way to appreciative

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dependence. It did not take long to become both physically and emotionally dependent on the iron lung. It could all too easily become a “comforting womb,” a “benevolent tyrant,” an “overprotective mommy.” The prospect of leaving its protection and relying once again on weakened and atrophied muscles to breathe was agonizing and called up awful memories of struggling as paralysis spread across the chest. Just as the initial fear of the iron lung had to be overcome if these men and women were to survive, so too their fear and anxiety about leaving the lung had to be overcome if they were to have any real chance of breathing and living outside the lung.

Although entombment in an iron lung may have represented some of the deepest fears associated with the polio epidemics, relatively few polio patients spent time in the large tanks and outside of photographs and newsreels few Americans actually saw someone in an iron lung. Wheelchairs and braces, the other two mechanical aids most closely associated with polio, were more familiar because polio survivors using them left the rehabilitation hospitals and went home, to school and to work. The frequent appearance of braces and wheelchairs in March of Dimes and NFIP promotional material and the presence of polio survivors who used these devices in public meant that a child in braces or a wheelchair was often the first image polio patients had when informed of their diagnosis. The language of the time, and even today, was of confinement and incapacity. Certainly many polio patients initially regarded the prospect of using braces and wheelchairs with apprehension and even fear because of the cultural connotations, but many also discovered that these devices could turn inability into ability and immobility into mobility. For boys and girls, men and women, whose legs were paralyzed and who had spent weeks or months in bed enduring painful stretching and exercises, wheelchairs and, to a lesser extent, braces meant liberation and freedom to move about the hospital and eventually outside it. Getting one’s first wheelchair or set of braces was also often a sign of progress. It meant that your muscles were getting stronger. And there was always the initial hope that, like the children in the March of Dimes material, you would finally shed the braces, park the wheelchair, and rise up and walk again unaided. That didn’t always happen, of course, and thus many survivors eventually had to come to terms with the realization that they would always need some form of mechanical assistance to walk or to be functionally mobile.

For polio patients with paralyzed or weakened leg muscles, a wheelchair was

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usually the first means of mobility in the rehabilitation hospitals. In some cases, however, they had to overcome widespread associations of wheelchairs with weakness and surrender before they could enjoy the mobility it provided. Families, doctors and nurses, and society in general held up walking as the ideal. For example, Dr. Joseph Barr[22] speaking at the first International Poliomyelitis Conference in 1948 declared that "practically every adult and most children with involvement of the lower extremities should be given the opportunity to attempt to walk without braces." Surgical techniques, he thought, had progressed sufficiently to make this possible. In Barr's view, reliance on any kind of "apparatus" was "an admission of defeat on the part of the surgeon in charge of the case." In recalling their initial reactions to the prospect of using a wheelchair, polio patients suggested the power of the stigma associated with using a wheelchair. Robert Lovering[23] admitted that his "first time sitting in a wheel chair exposed [his] own attitude toward disability." After two months in bed, the therapists lifted him out and sat him in his "new, shiny wheelchair." While he was jubilant to be out of bed and sitting up, he thought, "I don't want anyone to see me in a wheelchair; hospital staff and patients, and my family are ok, but never a stranger." He remembers that he was "overwhelmed by the feeling of shame, having to sit in a wheelchair and not being able to do what the great majority in society could do—walk around without the assistance of any aid or person." Leonard Kriegel[24], who eventually learned to walk "on legs encased in steel and leather," acknowledges that he shared the widespread antipathy to the wheelchair. Like almost all of the other boys he knew during his two years at the New York State Reconstruction Home, Kriegel believed "that using a wheelchair signified some sort of spiritual surrender." Using a wheelchair simply made you less of a man.

Whatever their initial aversion to the wheelchair, most polio patients quickly discovered that the device provided them with welcome mobility. Robert Lovering admits that his feelings of shame at needing a wheelchair dissipated within a week, "for suddenly I was mobile again and with great effort could at least propel myself down the hallway or around our men's ward." Peg Kehret remembers learning how to transfer from her bed to her wheelchair as "a giant step on the road to independence." It meant that she could go where and when she wanted without assistance. In spite of his ultimate desire to free himself of the wheelchair, Leonard Kriegel found that using his first wheelchair in the rehabilitation hospital was "a triumph" that freed him "from the narrow confines of the ward to the wider world." He was now free, "freer, as far as the adult world was

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concerned, than [he] had ever been before." During the long, painful months of learning to walk with braces and crutches, Kriegel much preferred the easy mobility that the wheelchair provided. As he put it, "with the braces and crutches, I faked it; with the wheel chair, I lived." Although he, too, would eventually learn to walk with braces and crutches, Lorenzo Milam[25] first regained mobility at Warm Springs in a wheelchair. Getting six hours and more of "butt time" in his wheelchair gave Milam "the newest and most precious freedom: independence." As he wrote, "In de pen dence. Jesus Lord, how great it is. To wheel to lunch and supper on my own. To careen down the hall on my own. To take my own dump by myself. I am my own person!"

Once they discovered that wheelchairs meant mobility and freedom rather than confinement, these polio patients quickly adapted to this mode of locomotion. I suspect that in virtually every rehabilitation hospital there were wheelchair races where there were two or more patients to compete. Girls were as likely to participate in these contests as boys were. The men in Robert Hall's[26] Veterans Administration Hospital treated their wheelchairs like the cars they would have driven if not for polio: "In a minute, we could be almost anywhere else in the hospital in our wheelchairs. They were speedy, and we worked on them to make them even more speedy. We constantly bugged the crew in the maintenance room for oil or graphite for the axles so the wheelchairs would roll with less friction." Hall and his friends soon learned wheelchair stunts. They had contests where they rocked the chairs back on the rear wheels and tried to outlast one another balancing on two wheels. Young men were not the only ones to pull wheelchair stunts. For example, Peg Kehret considered herself a "daredevil" in her chair. Like Hall and his friends, she soon learned how to "pop a wheelie." These young men and women quickly discovered that the joys of freedom and mobility displaced their feelings of shame in having to use a wheelchair.

Although they quickly adapted to using and relying on the wheelchair in the rehabilitation hospital, taking a wheelchair home or out in public was still a daunting prospect. Janice Gradin[27] was 16 when she returned to school using braces and a wheelchair. She found It "hard" to go into the community. She "wasn't ashamed of using a wheelchair or Kenny sticks" in the hospital, but at school or church it marked her as "different." While Allen Lee felt he had made a good adjustment to using the wheelchair fulltime, he found it harder to accustom himself to "the look that was pity in another's eyes" when family and friends saw

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him in his chair. And Jan Little found that while her neighbors welcomed her back into their community, there "was still the pressure to learn to walk. Walking was proof that you had worked hard and overcome your disability. Wheelchairs were associated with old or sick people." Outside of her "farming community being in a wheelchair carried a fair amount of shame." Finally, Robert Lovering remembers an incident several years after leaving the hospital when a "well-meaning lady" in a department store said to him sympathetically, "'Isn't that wheelchair a terrible thing?'" He replied, "'No, it is my best friend because I would look awfully silly right now without it." His response is indicative of how many polio survivors ultimately came to feel about their chairs.

As with wheelchairs, the prospect of getting braces often called up the iconic March of Dimes images of a young child, legs encased in leather and steel braces, leaning on fore-arm crutches. In many ways, this ubiquitous image defined what it meant to be a cripple during the decades of the polio epidemics. The thought of wearing a brace for life distressed many polio patients whose leg muscles were atrophied or weakened. When Ray Gullickson[28] learned that his physician had written that he would always need to wear a brace, he was shocked. It had "never occurred" to him that he wouldn't walk again or that he might need bracing. He remembers "sitting there, shaking [his] head in utter disbelief and thinking, 'Absolutely not! I will not wear a brace.'" Similarly, Stuart Goldschen[29] was told that he, too, would always need bracing to walk. But he soon began to make such significant improvement that he didn't need braces. He remains convinced that his "fear of having to wear those braces caused [him] to get better." When Edward Le Comte was learning to walk with his braces, the mirror in the therapy room had a kind of "morbid fascination" for him. It showed him how "unnatural and laborious" his walking was. The therapists promised him that he would "get used to it in every way; which was exactly what [he] feared, it being appalling, if saving, what one *does* get used to." Leonard Kriegel was fitted for braces after he had already achieved mobility in his wheelchair. For him, getting braces forced a moment of awful recognition. As he uneasily stood for the first time in his new braces with "the wooden crutches thrusting painfully into [his] fleshy armpits," his "mind first whispered the word 'cripple'" to him.

In spite of their weight and discomfort, polio survivors often accepted their braces because they enabled them to do things that otherwise would have been impossible. Being able to function, to move, was ultimately more important than

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appearances. For example, David Oakley[30], who has worn two full-leg braces for nearly 50 years, has “never ever hated [his] leg braces”: “They have been my friends. I’ve needed them and they have always been there for me.” He wonders how anyone could “hate their braces, when they have given us our freedom.” Joyce Ann Tepley[31] made every effort to relearn to walk without braces following polio, but after falling off playground equipment and breaking her unbraced leg, she decided to give “up the goal of walking without braces in favor of feeling safer.” Wearing braces made it easier to be involved in Girl Scouts and with friends and she concluded that “there were other things [she] was more interested in doing than concentrating on walking without braces.” Similarly, after several years of walking without braces, Richard Owen[32] chose to go back to wearing a leg brace. It was at the end of his first year of medical school, he was doing a lot of standing and walking, and he decided he would be “a lot more comfortable” wearing a brace. Owen noted that Sister Kenny, who had treated him during his rehabilitation, would not have approved of his decision, but “when you balance out function as opposed to what she thought was normal gait, I had to go for function.”

In spite of their usefulness, polio survivors nonetheless tried to shed their braces as quickly as possible, sometimes without explicit permission from their physicians. Discarding one’s braces was another sign of recovery and return to something approaching a normal life. Most polio patients gave up their braces when their physicians decided bracing was no longer necessary. Not all doctors, however, were as cavalier as Mary Ann Hoffman’s[33] Shrine physician who, after examining her and her brace, declared, “‘We’ll just throw this thing away. It’s nothing but a mouse trap.’” In her case, surgery had made the brace redundant. However, many other polio survivors and their families made the decision largely on their own. Survivors generally abandoned braces when they discovered that they could function just as well without them. Diane Keyser[34] remembers that her brace broke after she had worn it for about a year when she was in high school. The brace was sent to be repaired, but by the time it was returned, Keyser “had learned to walk without it,” and she went without a brace for nearly forty years. June Radosovich[35] wore a body brace for “seven or eight years” to support weak muscles in her trunk, but she eventually reached a “point where [she] did well without the braces, so [she] stopped wearing them.” Charles Mee[36] worked hard to achieve his goal of walking without braces. When he was finally able to keep his “knee straight and fake walking on [his] left leg,” Mee “took off [his] leg

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brace and got around with just [his] two crutches." For Mee, "to be out of the brace was wonderful; what was even more wonderful was not to have to wear the ugly shoes in which the brace needed to be anchored." For Christmas that year his sister gave him "the mark of extreme coolness for adolescent boys in the fifties: white bucks." Other polio survivors removed their braces when they thought no one in authority was watching. For example, Jim O'Meara's[37] mother was "very adamant" about his wearing his arm brace all the time, but when he played with his brothers, he would "just take the damned thing off and throw it on the ground." At school he wore it in the classroom, but at recess he removed it once again. His mother nagged him about wearing the brace all of the time, but he persisted in taking it off when he thought he could get away with it. One polio patient undoubtedly spoke for many others when her current physiatrist asked her why she ever stopped wearing a brace, and she replied, "Because I was 13." Of course, not all polio survivors could shed their braces, but those who could generally did so as soon as possible, even if, from a strictly medical point of view, they might have been better advised to keep wearing them. But the temptation to appear more normal by discarding your braces was simply too strong.

Other young men and women eventually concluded that wheelchairs offered them greater mobility with less effort. They made this discovery only by trying repeatedly to walk with braces and crutches. Given their lack of muscle strength and control, some of them found trying to walk a harrowing experience. Paul Reitmeier[38] remembers that for years his parents or therapists would get him out of his wheelchair and stand him up with his braces and crutches. But he never felt comfortable standing, let alone walking. As he put it, "And there I am hoping, geez, don't fall over. My balance was terrible. OK. Take one step. I remember one step. I always remember, God, if I just lean back I'm going to fall over backwards." Finally, after several years somebody said to him, "If you're going to give up, you know, you're going to be in a wheelchair." And he recalls thinking, "Look it, I think I need to be in a wheelchair." Even though he knows he made the right choice, Reitmeier still has "guilt feelings" wondering if he "should have tried harder." Jan Little[39] also remembers the pressure she felt in rural Wisconsin "to work hard and learn to walk." Several times a week her mother drove her twenty miles to work with a therapist. The therapist would "prop [her] up on braces that reached to [her] waist, re-enforced by a corset that reached to [her] armpits" and Little would then practice walking. Usually, she "imitated a tree." She would "sway back and forth a few frantic moments, then crash to the ground, maintain-

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ing a straight position" as she fell. Ultimately, nothing worked and Little relied on her wheelchair for mobility. Like Little, Allen Lee's therapists tried to get him to walk. His leg braces went to his waist. With "steel brace corset" to keep him from bending at the waist and arm braces to keep his arms from buckling, he felt more like a "telephone pole" than a human being. He kept his balance but his "feet felt like tons and tons and tons of bricks. No matter how [he] tugged and pulled they stuck to the ground." He "struggled" for "four months" and "made no progress." Gradually he concluded that life in a wheelchair would be easier than continuing the struggle to walk, although he found it "far harder to adjust" family and friends to his using a wheelchair.

At some point during the long rehabilitation from polio most survivors reached a stable plateau. Perhaps their muscles had recovered sufficiently so that they could leave the wheelchair, discard their braces and crutches, or spend long periods outside the iron lung. In other cases they adjusted to the necessity to continue to use these mechanical assistive devices permanently. Most survivors expected that they would sustain their maximum level of recovery for the rest of their lives. Unfortunately, beginning decades after their acute illness, polio survivors in the 1980s began reporting increased fatigue as well as increased muscle weakness and pain. In addition, many found it more difficult to work and to carry out the normal day to day activities of living. To their dismay, many polio survivors found themselves once again confronting the necessity for mechanical assistance as their bodies failed them anew. The familiar fears and anxieties about using mechanical assistance recurred, but now they were heightened by a sense of failure. As Dr. Julie Silver[40] has observed, "so deeply ingrained was the doctrine of discarding equipment that many survivors today view using any new device as 'going back to being a cripple.'"

Years after they had initially struggled to accept mechanical assistance for their paralyzed bodies, polio survivors had to once again confront their fears of being crippled or disabled as they considered whether to return to using devices they had once discarded. It has been hard. For example, as Doris Staats's[41] post-polio symptoms increased she "was devastated and felt out of control." The prospect of "new orthotic devices was both difficult, and at times, devastating." Hugh Gallagher had used a manual wheelchair for some forty years when he began to lose significant "muscle power and endurance." Even as his post-polio problems increased, he resisted getting an electric wheelchair. To go from a manual to an

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electric chair was to admit failure. As Gallagher put it, “Electric wheelchairs are for *crippled* people, not for folks like me. In my mind’s eye, I am one of those lean, mean athletic wheelies.” What Gallagher discovered after he got new electric machine and began to use it regularly was that he could do things he had given up because he no longer had the strength or energy. Although he still sometimes has feelings that he has “given up, given in, after all these years of struggle,” he also acknowledges that the electric wheelchair has “changed” his life. He is also able to say, “I am not a failure, I have not given up, I am just sensible.” Post-polio syndrome has also forced Leonard Kriegel to change his reliance on assistive equipment. As a teenager Kriegel had committed himself to becoming “a crutchwalker, no matter what the cost.” As he strengthened his upper body and propelled himself through the streets of the Bronx, he “refused to think about a wheelchair as an alternative to walking on braces and crutches.” He came to believe that his manhood was at stake and “that using a wheelchair signified some sort of spiritual surrender.” Some forty years later, when age and post-polio have worn down his body, Kriegel faced returning to the wheelchair he had worked so hard as a young man to escape. It is not only his body that his changed, so has his attitude. He discovers that he no longer wants to live up to his youthful idea of himself and is inclined to say “To hell with it!” Somewhat to his surprise, “getting back into the wheelchair was not the spiritual death [he] feared.” Whether they were fifteen or fifty and beginning to suffer from post-polio, polio survivors had very conflicted emotions about the mechanical devices that provided mobility, reduced fatigue, and increased function. To use them was to admit to failure, to accept that one was crippled. Yet most came to see that culturally ingrained attitude itself as crippling and to accept the necessity for mechanical assistance if they were to get on with their lives. Still, it was, and is, never easy.

The fund raising appeals of the March of Dimes using images of cute crippled children standing on braces and forearm crutches, sitting in wheelchairs, or confined to iron lungs was phenomenally successful. The very success of this campaign, however, heightened fears of polio’s ability to cripple. For the children and young adults who contracted the disease in the 1940s and 1950s, these images of crippling were often the first thing that came to mind when they were diagnosed with the disease. To use braces and crutches, a wheelchair, or an iron lung stigmatized one as a cripple. This cultural antipathy to these assistive devices meant that polio patients often had to overcome an emotional and psychological resistance to these mechanical aids before they could be beneficial in their

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recovery. The circumstances of their use, of course, differed significantly. Placement in an iron lung was almost always an emergency. As paralysis spread across the chest muscles, breathing became labored, and unless an iron lung was available death could come quickly. The monstrous green tanks sitting in the hall quickly became mechanical saviors. Doctors made decisions about braces and wheelchairs in the much less urgent setting of the rehabilitation hospital. Here patients had had a chance to see fellow polio survivors who were farther along in their recovery struggle with and use these devices. Still, many recall their initial anxiety that using braces or a wheelchair would mark them as cripples. Whatever their stigmatizing fears, most eventually discovered that the functionality of braces and wheelchairs more than counterbalanced the commonplace attitudes. Braces and wheelchairs were not confining they were liberating. They enabled you to rise out of your bed, to move around the ward and the hospital, and eventually to leave the hospital under your own power, even if that power was generated as much by your arms as by your legs. By confronting the cultural stigma associated with these devices and by in some sense embracing these mechanical "friends," polio survivors compensated for their paralyzed bodies and became functional in the wider world of home, school, and work.

NOTES

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3. Two relatively recent videotapes include substantial excerpts from newsreel coverage of the polio epidemics: "A Paralyzing Fear: The Story of Polio in America," produced by Nina Gilden Seavey and Paul Wagner, directed by Nina Gilden Seavey, PBS Home Video, 1998; and "A Fight to the Finish: Stories of Polio," produced by Ken Mandel and Dr. Tony Herring, directed by Ken Mandel, Texas Scottish Rite Hospital for Children and Ken Mandel Productions, 1999. For a discussion of the role of the film industry's support of the campaign against

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16. Marie Latta, “Personal Story,” *Memories: A Tribute to Polio Survivors,* A Special Publication of the Atlanta Post-Polio Association (Atlanta, GA: APPA, 1997), 43. For a similar reaction, see Kathryn Vastyshak, interview by author, Allentown, PA, June 25, 2002.
17. Allen V. Lee, as told to Melva Rorem, *My Soul More Bent* (Minneapolis, MN: Augsburg Publishing House, 1948), 14.
18. Louis Sternburg and Dorothy Sternburg, with Monica Dickens, *View from the Seesaw* (New York: Dodd, Mead & Company, 1986), 21.

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Readers interested in complete citations should consult the original article in the Journal of Medical Humanities, vol. 26 (Fall 2005), 173-190.

Please let us know how you feel about the statements in this article. Did you have some of the same feelings? Did you experience fears, self-consciousness, or lack of self esteem? Do any those feelings remain today?

Was polio a brief episode in your life, or are you dealing with it on a daily basis? What are some of your coping skills, both physical and emotional?

Send your thoughts or comments to: Rancho Post-Polio Support Group
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