



**TOO SICK TO WORK, TOO SOON FOR MEDICARE:
THE HUMAN COST OF THE TWO-YEAR MEDICARE
WAITING PERIOD FOR AMERICANS WITH DISABILITIES**

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ABSTRACT: In the United States, nearly 7 million people under age 65 qualify for Medicare due to severe and permanent disabilities. However, these individuals must wait two years after they are deemed eligible for Social Security Disability Insurance to receive this coverage. As a result, there are as many as 1.5 million men and women who are too disabled to return to work but who must wait to receive Medicare coverage for their health care needs. Nearly 39 percent are uninsured for at least some of this time, and 26 percent have no insurance throughout the waiting period. This report tells the stories of 21 individuals struggling to survive the 24-month waiting period. These real-life stories expose the financial hardship, pain, and suffering caused by the waiting period and provide evidence of the need for the swift enactment of legislation to eliminate the waiting period.

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In this report, these individuals give their accounts of what it means to become too sick or disabled to work, and to learn that it is too soon to get health care coverage through Medicare. In all cases, we have tried to stay as close as possible to the language and the spirit of the participants' stories.

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Thanks to the Fund's generosity, this report will shed light on the sometimes cruel effects of the policy of making people wait 24 months for Medicare benefits after they are judged too disabled to continue working. Increasing public awareness of these effects can generate congressional action to eliminate the waiting period, so that no American will suffer from it in the future.

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INTRODUCTION

In 1965, President Lyndon B. Johnson made the creation of Medicare—a federal health insurance program designed to meet the needs of older Americans priced out of the private health insurance market—a cornerstone of his Great Society. In 1972, President Richard M. Nixon signed legislation extending Medicare to people under age 65 with severe physical and mental disabilities. The promise of secure health care coverage to younger people, who through illness or injury had lost their ability to work, was a natural extension of a program that already brought health and security to older Americans.

However, people who are deemed eligible by the Social Security Administration for Social Security Disability Insurance due to severe and permanent disability receive Medicare coverage only after a two-year waiting period. That is, they must wait two years after receiving their first disability benefit check before becoming eligible for Medicare. As a result of this policy, there are as many as 1.5 million men and women who are too disabled to return to work but who are waiting to receive Medicare coverage for the health care they need. Of these, nearly 39 percent are uninsured for at least some of the time during the waiting period,¹ and 26 percent have no insurance throughout the waiting period.²

This report tells the stories of some of those Americans.

The majority of people who become disabled were, before their disability, working full-time jobs and paying into Medicare like all other employed Americans. But what happens when, like Ralph Payette, they have a welding accident, or, like Deborah Turnage, they are diagnosed with a muscle disease? Life takes a mean turn, and at the moment these men and women need coverage the most—just when they have lost their health, their jobs, their income, and their health insurance—federal law requires them to wait two full years to become eligible for Medicare.

In one tragic and regrettably typical story, Jim Waterhouse was left with \$50,000 in debt and compromised health caused by lack of medications and treatment after two heart attacks, severe spinal compression, diabetes, and anemia. Other individuals, like Darla Polasek, see their marriages fall apart as they wait. Still others, like Elaine Gilbertson, attempt suicide to escape the shame and depression of having to ask for handouts and go without treatment. Many sell their homes or go bankrupt. And more than 16,000 people—like Stan White—do not make it through the waiting period. They die before their Medicare coverage ever begins.

For years, the cost of ending the waiting period has been known. Expert analyses have shown providing men and women with Medicare at the time that Social Security certifies them as disabled would cost \$8.7 billion annually³. This cost would be partially offset by \$4.3 billion in reduced Medicaid spending by Medicaid, which many individuals require during the waiting period. In addition, untold expenses borne by the individuals involved could be avoided, as well as the costs of charity care on which many depend. Moreover, there may be additional savings to the Medicare program itself, which often has to bear the expense of addressing the damage done during the waiting period. During this time, deferred health care can worsen conditions, creating additional health problems and higher costs.

The 24-month waiting period was instituted to save money and keep people from “gaming the system.” But as the sister of Stan White, the man who died waiting for his Medicare coverage to begin, said, “People who are genuinely gaming the system have the time to wait it out. It’s those who truly need help who don’t have time on their side.” Ultimately, the financial savings resulting from the waiting period is dwarfed by the human cost.

Some members of Congress have attempted to prevent at least some people from falling through the cracks of the health care system when they most need care. On December 15, 2000, the 106th Congress eliminated the waiting period for people with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease. Calling the 24-month waiting period an “arbitrary and cruel restriction,” Senator Robert Torricelli (D–N.J.), an author of the bill, remarked that eliminating the waiting period “will mean that no ALS patient will ever again be faced with the indignity of going bankrupt while waiting for Medicare assistance.”

Meanwhile, people with other disabling conditions continue to suffer. Bills to end the waiting period were introduced in the 109th Congress in both the House and the Senate, but floor votes did not occur and committee action was not taken. As the 110th Congress begins its work, there is an opportunity to bring new attention to the issue. Senator Jeff Bingaman (D–N.M.) is planning to reintroduce the bill to eliminate the Medicare waiting period.

The stories of suffering and pain and of will and endurance that follow in this report should serve as guideposts for a national policy that offers health care—not delay—to Americans who are struck with disabilities. This report puts a human face on the toll our national policy extracts on the individuals who face delays, expenses, and forgone health care at a time when they are most vulnerable and most in need.

JIM WATERHOUSE

In September 2001, Jim Waterhouse had two heart attacks and took six weeks of short-term disability from his job. In his late 50s, he already suffered from back pain that had begun years earlier, in his 20s. A variety of treatments, including two surgeries, had failed to improve his back condition, which was eventually diagnosed as spinal stenosis, or a compression of the nerves in the spine. Pain caused by the stenosis was exacerbated by arthritis. In addition, Jim had only one leg, the other having been amputated as the result of an earlier hunting accident.

Jim worked as a field engineer at a company in the Philadelphia area. Much of his work was manual, consisting of tasks like taking measurements and making field sketches. The combination of heart attacks and back pain made this work nearly impossible. As Jim recalled, “I’d go out, and I’d walk through the unit, and my back would go out and I was out of breath. I knew I couldn’t do it anymore.”

Jim discussed the problem with his supervisor, who made it possible for him to keep his job by assigning him less manual tasks. But in 2004, when work slowed at the company, he was laid off.

Both Jim and his wife, Martha, became uninsured because they could not afford the \$900 per month Consolidated Omnibus Budget Reconciliation Act (COBRA) premium that would have allowed them to extend their coverage under Jim’s employer health plan.⁴

At that point, Jim could only visit his primary care physician when his medicine needed to be adjusted and saw his cardiologist only when he needed to have blood tests. His need for care, however, was increasing: the back pain had become worse and he had developed diabetes. Jim paid out-of-pocket for visits to his primary care physician, a radiologist, and a cardiologist. The blood tests alone cost \$150, and he soon realized that without insurance he would not be able to sustain even the little care he now received.

In addition to physician checkups, Jim required seven prescription drugs, primarily to strengthen his heart and reduce arthritis pain. Because he could not afford these medicines, he turned to the Internet for information and assistance and learned that he qualified for certain Patient Assistance Programs run by pharmaceutical companies.⁵ These programs allowed him to fill his prescriptions for free or at discounted rates.

Despite this assistance, Jim knew that he still needed health insurance. He began a desperate search for a job—desperate because no employer would hire him. With no other options, Jim went to his local employment office where he was told that his age and

poor health rendered him unemployable. The employment office recommended that he apply for Social Security Disability Insurance (SSDI).

Jim applied for SSDI and asked whether this benefit would include the option to purchase affordable health insurance. Social Security told Jim about the 24-month waiting period for Medicare.

Jim realized that it would be difficult to afford health care during the waiting period on top of regular household expenses. To ease the blow, Jim re-financed his family home and put the money into an account called “on-hand cash,” which he hoped would cover major expenses— including health care—until he became eligible for Medicare.

He also applied for health benefits from the Department of Veterans Affairs because he had been a medic in the U.S. Air Force for four years, though never stationed abroad. Jim was rejected for these benefits because his income and service did not qualify him.

In the fall of 2005, Jim was approved for SSDI. Around the same time, his primary care physician diagnosed him with anemia and told him to have a colonoscopy. Jim could not afford the procedure. “Without insurance that was out of the question,” he said. Instead, he bought iron pills that he hoped would prevent the anemia from worsening before he got Medicare.

In December 2005, Jim began to receive \$1,794 per month from SSDI. At this time, his wife had begun to work on a part-time basis, but her income was small and her job did not offer health insurance benefits. Jim felt financially vulnerable.

During the winter of 2006, Jim began to feel increasingly short of breath, but ignored the problem. Before suffering his heart attacks, Jim had been diagnosed with sleep apnea, an interruption in breathing during sleeping. At first he had a continuous positive air pressure machine that helps people with sleep apnea breathe normally throughout the night. But because he did not have health insurance he could not afford to replace the \$100 mask that was required for the machine, and when it appeared that the machine itself needed to be replaced, he could not afford the \$1,000 for a new machine.

At the same time, Jim worried that his diabetes was getting worse. Without insurance, the only diabetes management tool he could get was a blood-glucose meter, which he received for free for taking a pharmaceutical company-sponsored class at a hospital. However, he could not afford the \$95-per-month test strips the meter required four times per day. Instead, he checked his blood-glucose level once per day or less.

During this time, Jim also went without his annual check-up for the prosthesis he wore in place of his leg. He also went without the new \$600 liner that the prosthesis required annually. By March 2006, Jim's savings were nearly gone and he still was having trouble breathing. Finally, he made an appointment to see his primary care physician, who immediately sent Jim to the hospital's emergency room due to a dangerously low hemoglobin count. Jim was hospitalized for five days and amassed a \$46,000 bill that he could not pay.

During Easter weekend, Jim noticed a small black spot obstructing sight in his left eye. "I thought I was seeing the cat out of the corner of my eye," he recalled. The spot grew and soon obstructed around 80 percent of Jim's vision, whereupon he realized that his retina, which had detached 10 years earlier, had detached again.

Jim immediately visited the retinal specialist who had treated him before. He agreed with Jim's diagnosis. The specialist attempted to force Jim's retina back into place, a procedure that failed but nonetheless cost \$900. The specialist reduced the bill to \$400 when he learned Jim was uninsured and referred Jim to a hospital that specialized in eye care. At this hospital, another procedure to repair Jim's retina failed. Finally, Jim underwent an outpatient surgery that reattached his retina. Even after the hospital agreed to reduce the charge, the total cost was \$4,000. What's more, the surgery left an oily residue on Jim's eye that needed to be removed through a laser treatment. He decided to go without that treatment until he becomes eligible for Medicare.

In the summer of 2006, Jim was contacted by a collections agency and ordered to pay the \$46,000 bill he owed the hospital that had treated him for anemia. Jim could not pay and talked to a lawyer about the possibility of declaring bankruptcy. The Medicare Rights Center intervened on his behalf, writing a letter to the hospital requesting charity care. The hospital agreed to reduce the bill to \$6,500 and worked out a \$150 per month payment plan. While these bills are a financial strain for the Waterhouses, charitable write-offs and payment plans have kept them from declaring bankruptcy. If Jim had continued to have access to primary care, his anemia could have been treated and this expensive hospitalization and the resulting financial strain it caused could have been averted.

Jim became eligible for Medicare in January 2007. When asked about the difficulties of being uninsured, he said, "I tried to put off medical care until I became eligible for Medicare, which complicated my condition." Jim added that asking for charity and constantly negotiating payment plans has been "humbling and embarrassing." "I always had a good job with medical insurance, and never had to go through anything like this before," he said.

JO HENDERSON

Jo Henderson had finished raising her children and was working as the director of admissions for a Missouri college when she noticed trouble with her vision. She had been diagnosed years before with macular degeneration—a loss of eyesight that eyeglasses cannot correct. The disease had progressed so slowly that—until now—she had managed to ignore it.

Jo was making a comfortable salary. Although she had lost a portion of her savings during a recent divorce, she was not concerned because she planned to continue working for many more years. But now she found herself unable to read most documents; her eyes were so sensitive to light that she had to wear sunglasses all the time. Finally, at the age of 63, her eyesight became so bad that she was forced to leave her job and apply for SSDI.

Jo was quickly approved for SSDI, but soon realized that her \$1,110 per month check would not cover food and other necessities, as well as the \$360 per month to keep her employer health insurance through COBRA. Jo wanted to continue going to her ophthalmologist so he could monitor her eyesight and keep her abreast of any new treatments. In addition, Jo needed health insurance because another doctor had found nodules on her thyroid and prescribed medicine to treat them. The doctor needed to watch Jo to determine whether the nodules had stopped growing.

Despite the need to see her doctors regularly, Jo dropped her health insurance after six months because she could not afford COBRA coverage. Worried that she would not be able to stay out of debt, Jo resolved not to see her doctors or dentist. This situation was new to Jo, who had always worked and had health care. Uninsured for the first time in her life and in the process of becoming blind, Jo recalled that for the next six months she “sat around and cried.”

During this time, Jo had no idea whether the nodules on her thyroid were growing, but she felt fortunate that her doctor agreed to continue prescribing the medication to treat them until she received Medicare coverage and could return for monitoring. At the same time, Jo was constantly worried about her worsening eyesight and her financial situation.

Jo linked the stress created by her rising debt, the frustration over having to wait another year before she would become eligible for Medicare on her 65th birthday, and her continued loss of eyesight to a recurring heart problem evidenced by rapid, uncontrollable

beating. Frightened by the severity of this problem, Jo finally paid to see a cardiologist, who gave her a new diagnosis of a cardiac arrhythmia called atrial fibrillation, adding \$2,500 to her outstanding medical bills.

The cardiologist prescribed a blood thinner Jo could not afford, but his office agreed to provide free samples. He told Jo to return so that he could determine if the medicine was working and, if not, prescribe a new one. But unable to pay the first bill, Jo felt she could not make another appointment. Fortunately, her cardiologist agreed to prescribe various medications without her coming in for an appointment, until, through trial and error, they found one that worked. The cardiologist told Jo that she needed to have a blood test every three weeks so he could review the results and adjust the dose. Since she could not afford these tests, Jo decided to self-prescribe: if she woke up with blood in her mouth, she knew she should take less of the blood thinner.

Even though she was receiving free samples of the blood thinner—which would have cost \$140 per month—Jo’s medication costs were totaling \$250 per month. Under increasing financial pressure, she sold her house, moved into a one-bedroom apartment, and considered moving to a low-income senior facility. In the meantime, she was beset by new problems. Her scalp began to itch unbearably, but seeing a doctor “was not even an option,” she said. She worried that the prescribed medication had failed to treat the nodules on her thyroid, but could not afford to return for monitoring. Embarrassed to ask her doctors for more charity or her family for help, Jo had never felt so isolated or dependent on others. “I had to decide whether I was going to buy food or medications,” she said. She began going to a food pantry run by a local charity. “I couldn’t believe that after all those years of working I had to do this,” she added.

During the spring of 2006, Jo’s daughter found a local service for the blind that taught Jo how to use a cane, gave her a device to magnify text, and provided a discounted car service for transportation. The service allowed Jo to regain some control over her life; she was even able to begin teaching an online class for a small income. The increased mobility also allowed her to teach a continuing education course at a local school, eventually using equipment from the service for the blind.

Jo got Medicare in May 2006 when she turned 65—she did not have to complete the 24-month waiting period. As she put it, she was “so thrilled.” During the first month, she visited her primary care doctor and cardiologist, who tested her blood and adjusted her medication. She made an appointment with her ophthalmologist, who referred her to a macular degeneration specialist to determine whether anything could be done to retard or

prevent further loss of eyesight. She visited the doctor who had found nodules on her thyroid and learned that they had stopped growing. She also went to a dermatologist, who told her that her scalp discomfort was a result of the medications she was taking and prescribed a cream that eliminated the itch.

During her year waiting for Medicare, Jo had been concerned because she regularly woke up with blood in her throat and mouth, which was understandably frightening to her. After receiving Medicare, she was able to have her blood thinner adjusted by her cardiologist and no longer experienced the problem. Jo also enrolled in a Medicare private health plan that offered prescription drug coverage. Her drug copays are now \$5 and she can afford all her prescriptions. For the first time since being approved for SSDI, Jo can pay her bills and is able to afford the medical treatment and medications she needs. Her improved health care situation has encouraged her to continue teaching a class once a week.

While in the waiting period Jo said she “was counting down the days until Medicare.” She still has roughly \$3,000 in medical bills accrued during her wait, but hopes to pay them soon. “This year is so much better, my spirits are better, and now that I have Medicare I can breathe. It’s like a weight off my shoulders,” she said. Of the 24-month waiting period, Jo concluded, “Declared disabled and not given health care—what an oxymoron.”

STAN WHITE

Stan White lived in Gaffney, S.C., with his wife and two children. For 30 years he worked for a textile company, developing the nickel-plated machinery used to make cloth patterns. A talented artist, Stan spent his free time creating promotional artwork for community events and drawing cartoons for his local paper. Then, in January 2002, when he was 56, Stan had a stroke that partially paralyzed his right side. Forced to leave his job, he applied for SSDI. He was able to remain insured through COBRA, but only because his former employer helped pay for it.

Shortly after suffering the stroke, Stan developed speech problems. Three months later, he had a seizure. Although an MRI revealed no abnormalities, Stan's speech continued to worsen, and in July a doctor found a tumor in his brain that had grown to the size of a lemon. The doctor diagnosed Stan with an aggressive form of cancer, put him on steroids, and removed the tumor. The treatment failed to eradicate the cancer, and the doctor said it was futile to continue treatment, giving Stan four to six months to live. That spring, Stan was approved for SSDI and began to receive benefits in July.

Around the time of Stan's cancer diagnosis, his sister, Marlene, saw a news story about a cancer treatment being tested in Alabama. With the hope that it would help cure Stan or buy him more time with his family, Marlene called the program to discuss Stan's situation. She was told Stan's chances of meeting the clinical trial's criteria were slim, but she persevered and was able to get Stan into the trial. In the autumn of 2002, doctors removed the remaining cancer from Stan's body and began administering the experimental treatment. Stan's COBRA coverage and clinical trial recompensation covered part of the cost of treatment, and Stan was able to afford the remainder.

Stan was cancer-free the following year, but his former company went out of business and stopped helping him pay for COBRA. The family's savings had already been drained by health care costs and COBRA payments.

In an e-mail message to friends Stan wrote, "Like I said, I am not afraid to go on when the Lord is ready for me, but I really want Shirley [wife] to be taken care of. I am afraid of the mounting medical bills and don't want Shirley to have to face that."

As a result, Stan refused to touch his retirement fund or to sell his home during these crises. But because his SSDI payments were too high for him to qualify for Medicaid, he could not continue paying COBRA and became uninsured.⁶

Stan and his family worried the cancer would return before he became eligible for Medicare. He remained uninsured because his preexisting medical conditions made private insurers unwilling to cover him. Stan and his family contacted several state senators to ask that an exception to the waiting period be made. Each time, they were asked to fill out multiple forms, only to receive the same answer: Stan had to wait for Medicare.

When Stan's sister Marlene asked one government official why individuals with disabilities must wait for Medicare, he responded that this stopped people from "gaming the system." After her experience with the waiting period, Marlene said, "People who are genuinely gaming the system have the time to wait it out. It's those who truly need help who don't have time on their side."

By now, Stan was having so much trouble speaking that it was often impossible to understand him. He started an e-mail newsletter to keep in touch with his extended family and friends. Unable to draw, but still interested in art, he included photography and pieces of his writing in the newsletter.

In February, less than one year before he would become eligible for Medicare, Stan learned that the tumor had returned. Without health insurance, every treatment was too expensive and his condition quickly deteriorated. With no other option, Stan and his family begged the hospital that had run the clinical trial for charity care. It was only after relentless advocacy by his sister Marlene that Stan was admitted to the hospital as a participant in the same trial. Though Stan's renewed participation in the clinical trial afforded him treatment, it limited his options.

Normally, treatments that fail to permanently put cancer into remission are not repeated because they often prove even less successful the second time. Because Stan had not responded to the clinical trial's treatment the first time, he and his family wanted to try a new treatment. But the charity care required that Stan receive the same treatment he had received earlier. At this point, Stan was too weak to travel; fortunately, his family located a volunteer pilot willing to subsidize his flight to Alabama.

The experimental treatment—Stan's last resort, according to his sister—was not successful. By the time Stan became eligible for Medicare in July 2004, the cancer had robbed him of speech and nearly all movement. He received Medicare coverage in time to receive hospice care, and died in September 2004.⁷

"My brother worked for over 40 years paying taxes, and he had paid into Medicare since it was established," Marlene says. "He worked hard to take care of his family, neighbors, and country [Stan was a veteran], but never received the benefits of the system he supported."

RALPH PAYETTE

Ralph Payette and his wife lived in Littleton, N.H., where he worked as a mechanic welder. In August 2004, as Ralph began to repair a car's exhaust system, a spark from the welding came into contact with some nearby fuel. As Ralph remembered it, there was "a great big flash, like a mini-explosion," and then his hand was ablaze. "By the time I got to the sink and got my glove off," he said, "my hand was a molten mess."

Ralph, then age 45, was rushed to the closest hospital, where the emergency room physician cut his melted wedding ring off his finger and bandaged his hand. A few hours later Ralph was released from the hospital, and his wife took him home. He was instructed to stay away from work while he healed.

During the next four weeks, Ralph regularly saw a doctor at the hospital. The doctor instructed Ralph to keep the burn clean and, even though he could not move his hand or feel his fingers, said he could return to work soon.

In the meantime, Ralph was unable to afford the high COBRA premium to extend his employer health insurance. Because his wife's job caring for handicapped adults did not offer health insurance, Ralph and his wife became uninsured—but they were not overly concerned because Ralph planned to return to work. Additionally, worker's compensation was covering treatments for the injury and also paying him 60 percent of his salary.

But as weeks passed without the feeling returning to his hand, Ralph became worried. His hand began to swell, which his doctor diagnosed as an infection and treated with antibiotics. The swelling continued until, Ralph remembered, "It looked like I had a ski glove on."

Ralph returned to the emergency room. There, the doctor who initially had treated the burn recommended Ralph go to a larger hospital farther away. He suspected Ralph had reflex sympathetic dystrophy (RSD), a rare disorder characterized by chronic and severe pain, and apologized for not initially recognizing the extent of damage to Ralph's hand.

The workers' compensation office told Ralph to see one of its hand specialists. Ralph says the pain had become "unreal." He consulted several specialists who found that his nerves were damaged and diagnosed him with RSD. The majority of RSD cases, he was told, cannot be cured. During the next months Ralph's doctors tried to control his mounting pain and maintain movement in his arm. They prescribed occupational therapy, water therapy, and more than a dozen medications. Ralph's local hospital did not have sufficient therapy resources, so Ralph drove three hours round-trip to the major medical center nearly every day.

Workers' compensation covered this treatment, but Ralph soon learned it maintained a narrow view regarding the treatment his injury required. That November, Ralph's pain

became unbearable and he was hospitalized. The attending doctor refused to release him from the hospital until a stimulator—used to control the pain—was placed in Ralph’s back.

Workers’ compensation said the stimulator was not necessary. Ralph recalled his doctor arguing with the insurance company’s director while Ralph prepared for surgery. Even though workers’ compensation refused to cover the stimulator, Ralph’s doctor inserted it and assured him the hospital would charge the insurance company. Until months later when the insurance company finally acceded, Ralph worried he would be responsible for the bill.

During the winter of 2004, worker’s compensation refused to cover several medications Ralph’s doctors prescribed, again claiming they were unnecessary. Ralph began to experience extreme pain in his feet that slowly spread up his legs. “I tried to think it wasn’t there,” he said, but his pain specialist soon confirmed that RSD was now in both his legs.

Ralph was crippled by pain and steadily lost movement in his hand and legs. He was comfortable only when he took so much pain medication that he could not function. Ralph knew he could not return to work, and in the spring applied for SSDI.

Ralph’s SSDI application was mishandled. He was not awarded SSDI until December 2005, with the help of a workers’ compensation lawyer. However, he did not have to wait the usual five months to receive his first check because Social Security recognized he should have been approved earlier in the year. Instead, Ralph began to receive benefits in the winter of 2006. He would not get Medicare until the winter of 2008.

Ralph worried about his and his wife’s health and became increasingly depressed. Each visit to a primary care physician cost roughly \$80. He could only afford to see his primary care physician infrequently for medication to treat his depression. Ralph worried that he had other undiagnosed conditions, and that the quantity of medicine he took would negatively affect his health. His worries were compounded by uncertainty: his last physical exam had been before the accident.

During the winter of 2006, Ralph’s depression worsened and he continually worried that workers’ compensation would refuse the services and prescriptions he needed. He remembered himself as having once been a happy and active man. “It’s really hard to describe all the changes in my life,” he said. “I never suffered from depression before. I didn’t even know what it was.”

Previously, Ralph had loved to be outdoors and restored classic cars as a hobby. Now he could barely move his arm and legs. Ralph had six children and several grandchildren and sadly said, “I have grandchildren that I can’t run and play with.”

Ralph's specialists found that medications had lowered his testosterone level. To treat this, they prescribed shots that workers' compensation would not cover. Ralph had no choice but to keep mailing the bills to workers' compensation in the hopes it would pay them, thinking: "You wonder whether you'll get stuck with thousands of dollars worth of bills." The Payettes had built good credit throughout their marriage and now feared their credit would be ruined.

Earlier, one of Ralph's doctors recommended he find a lawyer to help force workers' compensation to cover the prescriptions and treatment the specialists thought were necessary. By this time, Ralph had been prescribed a second stimulator for his legs that workers' compensation would not cover. In the spring of 2006, Ralph and his lawyer took the insurance company before the labor board and asked the company to cover a leg stimulator and Ralph's testosterone shots. Ralph knew these treatments were necessary, but said he still could not escape the feeling that he was a "bad person, because I am a person in a heap of trouble, and it is going to cost them a heap of money."

Ralph lost the case because he did not provide enough evidence. He tried to cope with the pain through meditation his therapist taught him. "I just put myself into another place. I do whatever I can do to forget the pain," he said. "I pray a lot."

By fall 2006, Ralph and his lawyer had gathered the missing evidence and again took the insurance company before the labor board. By this time Ralph was desperate and recalled that he "lost it" during the case. "I just broke down," he said.

Ralph's lawyer was confident they had won. While Ralph waited for the decision, workers' compensation called to say they felt one of his pain medications was no longer medically necessary. Soon afterwards, the labor board ruled that the insurance company must cover Ralph's testosterone shots but not the leg stimulator. "I just couldn't believe it," Ralph said. By this time, RSD and constant pain had spread to Ralph's upper-thighs.

Ralph's doctors have since recommended ketamine infusions, which workers' compensation will likely not cover. Ralph is not sure what he will do or how he will survive without the stimulator. "I'm caught between some hard spots right now. I have to try something," he said.

Ralph will get Medicare in February 2008. Until then, he is afraid that workers' compensation will refuse to cover his other health care needs, like physical therapy and medicine. He is looking forward to seeing a primary care physician and getting a second stimulator, when he gets Medicare coverage. "If it weren't for the love my wife, children and grandchildren have for me, I wouldn't be here," he said.

JANET KING

For 25 years, Janet King worked as a medical social worker. She described her work as “beautifully interesting,” and found helping sick people accept and adjust to their diagnoses rewarding. Janet, a single wage earner, lived by the ocean, and commuted to San Francisco daily.

In 2003, when she was in her late 50s, Janet began to experience back pain. At first she thought it was “some kind of an aging process,” but as the pain worsened, she began frequently to lose her balance and fall. One day that spring, Janet fell to her knees. She had trouble getting up and was in so much pain that she went to the doctor. He diagnosed Janet with avascular necrosis in her hips and legs, a condition that causes tissue to die as a result of an inadequate blood flow.

By the time Janet received this diagnosis, the tissue around her right hip was so damaged it could barely hold her hip in place; sometimes the hip became dislocated. This condition was crippling and forced her to stop working in June 2003. She planned to apply for SSDI.

Janet had thought she might maintain her employer health insurance through COBRA until she was approved for SSDI, but learned that COBRA would cost \$510 per month, which she could not afford. Because she was not planning to retire early she had very little savings. As a result, until she began to receive SSDI, Janet’s only income was state disability insurance that she began to receive from her job one month after she stopped working. As a social worker, she fully understood the implications of being uninsured and felt “frantic.”

Before becoming uninsured, Janet had an MRI; the test confirmed she had avascular necrosis. Janet’s doctor said she needed a hip replacement and also found that multiple compression fractures in her spine. In addition, the doctor prescribed medication to treat a heart arrhythmia that Janet had had since birth. The combination of conditions was nearly unbearable. “I was in excruciating pain,” she said.

Janet recalled that her orthopedist once said, “It is so appalling that when a physician declares a patient to be physically disabled and a patient is clearly in medical crisis, that patient is totally thrown to the wolves.”

This perfectly describes what she felt occurred, she said, after her employer-based health insurance ended. Without insurance, Janet could not pay for a hip replacement. She

could only afford to occasionally pay out-of-pocket to see her orthopedist for pain and cardiac medicine. Janet's orthopedist also prescribed cortisone shots for her hip, which Janet usually went without.

Janet also went without basic medical care like regular physicals, mammograms, and vaccinations. Yet even forgoing routine health care, Janet still struggled to afford her household expenses and constantly worried she would develop a condition that would worsen without diagnosis and treatment.

It took several months for Janet to collect the large quantity of necessary information from her doctors and fill out the paperwork to apply for SSDI benefits. Social Security did not finish processing her application until April 2004, eight months after she had applied for the benefit.

In the meantime, without care, Janet's back and hip pain had steadily worsened. Even the weight of a sheet against her hip caused agonizing pain.

In March 2004, Janet fell on her apartment's concrete deck. She could not stand up and crawled to her phone to call an ambulance. At the closest hospital, an emergency room doctor took X-rays of Janet's hip and legs and told her, again, that she needed a hip replacement. The doctor gave Janet morphine to ease the pain but did not admit her to the hospital since she could not afford the hip operation without insurance. Janet was sent home.

Janet's monthly SSDI check barely covered her rent, medicine, and household expenses. Nonetheless, she soon received a \$7,000 bill for the ambulance and brief treatment in the emergency room, another expense she was powerless to pay.

To apply for emergency Medi-Cal, California's Medicaid program, Janet had to provide information from Social Security that explained her situation. Because Social Security did not finish collecting this paperwork until April 2004, Janet had to wait one month after her fall before she could complete her Medi-Cal application. When she finally received a letter from Social Security, it stated that she was recognized as having a permanent disability beginning the previous summer. Thus, she would receive Medicare in December 2005, 29 months after Social Security recognized the start point of her permanent disability. As a medical social worker, Janet had understood the Medicare waiting period to be 24 months from the date SSDI benefits were awarded, not from five months later, when SSDI benefits began. But she was wrong: she had to wait 29 months after being approved by SSDI before receiving Medicare.

With the necessary paperwork in hand, Janet was finally able to apply for Medi-Cal. She described the five months that she waited to be approved for this benefit—and thus gain the chance to have a hip replacement—as “the most painful five months in my entire life.” The pain was so intense that it often prevented Janet from sleeping.

By this time, Janet had sold her car to make ends meet. This misfortune came on top of the fact that—unable to afford her rent—she had been evicted. Janet loved her apartment by the ocean, but had been forced to move to a less expensive apartment.

Janet’s hip was finally replaced in August 2004, when she had “spent down” enough money to get Medi-Cal coverage. After the operation, she received rehabilitative treatment in a skilled nursing facility for 10 days. In addition to pain medicine and a calcium supplement, the staff gave Janet medicine for her heart condition. But once these prescriptions ran out, Janet often could not afford to replace them. Sometimes Janet skipped her medicine for more than 10 days at a time. She could not afford to spend down for Medi-Cal each month.

Individuals who make more than the monthly income limit for Medi-Cal—about \$600—can still qualify for the benefit by spending all income in excess of this amount on health care costs. Once they do this, they receive Medi-Cal coverage for the rest of that month. Janet’s income was above the Medi-Cal limit, so she would only receive the benefit when she spent her monthly income, except about \$600, on health care costs. Janet could not afford to regularly spend-down to the Medi-Cal limit because \$600 was not even enough to cover her rent. She wondered, “How could one be expected to survive on \$600?”

Between the month that Janet was first diagnosed with avascular necrosis and her operation, she lost 30 pounds as a result of stress, pain, and the high doses of pain medicine required to control her pain.

Around the time of her operation, collection agencies began to call and demand she pay the hospital bills from the previous spring. Janet could not afford to pay, but continued applying for Medi-Cal to cover them retroactively.

She recalled, “It was terrifying and caused me incredible stress, at a time when I already had medical problems.” If Medi-Cal refused to cover the bills retroactively, Janet would probably be forced to declare bankruptcy. She could not believe she was in such a crisis—particularly after working at the very same hospital the collection agencies were representing.

She felt vulnerable and pointed out, “Collection agencies for hospitals are rabid in collecting their payments, and they do not care if you have no food.”

The ambulance service that had transported Janet to the hospital for emergency care called daily until she wrote a desperate letter to the president of the company, outlining the steps she had taken to request that Medi-Cal reimburse the company and begging them to stop harassing her.

Medi-Cal finally paid a portion of Janet’s debts retroactively and a payment plan was created that Janet could afford. For a while, the hospital sent Janet bills that Medi-Cal had already paid. It was only after Janet sought the assistance of a Medi-Cal financial analyst that the hospital stopped contacting her.

Janet became eligible for Medicare on December 1, 2005. She finally saw a primary care physician and began to receive basic medical services. She was able to get physical and occupational therapy. More than anything, she valued the “peace of mind” Medicare offers. It took more than a year after Janet got Medicare to finish paying the debt she incurred in the waiting period. To Janet, the knowledge that she will not face debt if she has another accident and that she can receive the medical care she needs is invaluable.

About the 24-month Medicare waiting period, Janet said, “It is cruel and inhumane that individuals face this kind of punishment.” Yet despite the difficulty of the experience, she felt that, as medical social worker, she had a distinct advantage compared with most people who face the waiting period. “I was able to go through the 29 agonizing months before the safety net of Medicare was provided for me in much better form than many less informed and less tenacious individuals who are declared disabled.” she said. “It is appalling that we do not have a safety net in place to protect people in our country from this type of medical nightmare.”

PAMELA VOTAVA

When she was nine years old, Pamela Votava was diagnosed with polio and prescribed braces and physical therapy. A few years later, she recovered, going on to get a degree in teaching and begin a career in medical practice management. She married and raised two sons in Toledo, Ohio, where she and her husband continued to live after their children had grown. They hoped to retire and use their savings to travel, a shared interest that they had not been able to pursue earlier in their lives.

When Pamela was in her mid-50s, she began to notice that she sometimes had trouble walking. But the problem was not severe or frequent enough to concern her until a few years later, when it grew worse. At this point, Pamela talked to her doctor about the problem. After running some tests, he diagnosed her with post-polio syndrome, a condition that is characterized by a weakening of muscles that have been infected by polio. The symptoms begin as fatigue and, over time, tend to result in a loss of muscle function that can be severe enough to prevent swallowing. Post-polio syndrome cannot be cured but treatment can stop its progression.

After receiving this news, Pamela left her job as a medical office manager to see doctors who specialized in her condition. The specialists fitted Pamela with braces and crutches and prescribed physical therapy. At a visit with a specialist in New Jersey—a leading expert on post-polio syndrome—Pamela was advised to apply for SSDI. Until then, it had not occurred to her that she might never be able to return to work. Resigned to her situation and in her early 60s, Pamela applied for SSDI and was immediately approved in January 2005.

Until this point, Pamela had been able to pay the \$675 per month necessary to extend her employer health insurance for an extra six months. But she now realized that she would not get Medicare until January 2007 and she could not further extend her health insurance with COBRA because her former office did not employ enough people to qualify for this benefit. Pamela's husband had recently turned 65 and qualified for Medicare, but she now faced the prospect of being uninsured.

Pamela panicked. Without insurance, she could not afford to see her doctors—one appointment with the post-polio specialist in New Jersey cost \$600—or buy braces, which cost thousands of dollars. Pamela knew that without proper treatment her condition would worsen and she might die. She also knew from her experience in a medical practice environment that “many patients have to declare bankruptcy because of medical bills.”

Desperate for insurance, Pamela began to call private health insurance companies—but none would cover a person with her condition, even for an extremely high premium. Luckily, Pamela learned that, in Ohio, if COBRA cannot be used to extend employer health insurance, an individual can buy a policy through a former employer’s health insurance company. Armed with this knowledge, Pamela purchased an individual policy through her former employer’s insurance company at a cost of \$2,500 per month.

Pamela was able to begin treatment an hour away from home at a clinic in Ann Arbor, Mich., that specializes in post-polio syndrome. She was also able to get braces and, when the first braces did not function properly, she was able to replace them under her policy.

For several months—even before she purchased her private insurance policy—Pamela had been visiting her primary care physician every week. Now, the high copays for these visits combined with her monthly insurance premiums made them difficult to afford. Pamela had little choice but to forgo the therapy treatments prescribed by her doctor and discontinue physical therapy, which cost approximately \$160 per session, even with her new insurance policy.

In addition to treatment limitations, the private health insurance also limited Pamela’s care options. Pamela was restricted to doctors, therapists, and specialists in her plan’s network, none of whom specialized in her condition.

After being approved for SSDI, Pamela reported that she could not prevent the post-polio syndrome from progressing. She attributes the deterioration of her health to her inability to access specialist care and physical therapy. Another significant factor is the stress related to the possibility of becoming uninsured and the steady erosion of the savings she and her husband had accumulated over 40 years. To combat these stressors, Pamela rests frequently and visits her primary care physician every week.

Pamela cannot wait to become eligible for Medicare. Immediately after she receives news of her eligibility, she plans to make appointments with specialists at the post-polio syndrome hospital in Ann Arbor. She looks forward to not having to spend retirement savings on health care costs; already, she has paid around \$50,000 on premiums alone.

“Paying the individual health insurance premium and having very poor coverage in spite of the high premium” is very stressful, she said.

In addition to getting needed care, the Votavas plan to travel if Pamela’s health permits it, once she becomes eligible for Medicare and can see a doctor anywhere in the country.

When asked about her overall experience in the waiting period, Pamela said, “I am fortunate that I could cover such a high insurance premium and not have to live with the stress of being totally uninsured, but it has definitely impacted the quality of my life [during] the last two years. Many of the things [my husband and I] had hoped to do have had to be put off until I go on Medicare and get out from under such high premiums.”

As of November 2006, Pamela’s post-polio syndrome had progressed much faster than she had hoped; she had already lost the ability to walk and was depending on an electric scooter for mobility. Had it been available earlier, Medicare coverage might have prevented such a rapid deterioration of her condition.

RAYMOND WADDELL

Raymond Waddell lived in Woodville, Texas, with his wife and their four young children, all under the age of 12. For years, Raymond worked as an upholsterer, until, in his late 30s, he was diagnosed with small-cell lung cancer. This highly malignant form of cancer prevented Raymond from continuing to work, and he applied and was quickly approved for SSDI.

Raymond did not have significant savings. His only income was from odd jobs he picked up to support his family. Fortunately, Raymond's limited income and assets qualified him for Medicaid, a state health insurance program for low-income individuals.

During the months following his diagnosis, Raymond's Medicaid coverage paid for four cycles of chemotherapy. Raymond responded well and was about to begin radiation when he began to receive SSDI checks of about \$768 per month. The SSDI income pushed Raymond over the income limits for Texas Medicaid assistance and he lost his coverage. Without health insurance, the hospital refused to provide radiation treatments. When he asked what would have happened if he had begun to receive SSDI benefits while receiving chemotherapy, the hospital told him that they would not have been able to continue treatment. Raymond ironically recalled, "I got lucky that I did not get [SSDI] until I was through chemo."

Raymond would not become eligible for Medicare until the fall of 2007, 24 months after he began to receive SSDI benefits. Fortunately, a social worker at the hospital was able to identify another hospital where Raymond could get radiation treatment—but where he would no longer be seeing the doctors who had become familiar with his condition.

Raymond completed one course of radiation but could not afford follow-up care with an oncologist or primary care physician. Because he seemed healthy during subsequent months, this issue seemed minor. Then, one weekend, Raymond began to have seizures.

Raymond went to a nearby hospital but was sent home because he did not have health insurance and could not afford medical care. Panicked, the Waddells called a social worker familiar with Raymond's case. The social worker located a hospital that would admit Raymond; on the way there, he had another seizure. The social worker remembered that, despite his condition, Raymond's greatest concern was for his children, who were frightened by the seizures.

It was soon discovered that Raymond's cancer had returned and spread to his brain. Doctors diagnosed Raymond's condition as terminal and hospitalized him for the next two weeks. They also prescribed medicine to prevent seizures and treat pain and anxiety.

After Raymond was released from the hospital, he could not afford the medications that had been prescribed to help him in this desperate situation, and had to depend on a doctor for free samples. He relied on charity care to cover radiation treatments; the charity care, however, would not pay for additional chemotherapy sessions.

Raymond's social worker remembered him as a proud man who found it difficult to rely on charity. She says Raymond felt his doctors did not want to treat him because he could not afford their care. By this time, collections agencies were hounding him to pay debts for past medical care. "I paid taxes and Social Security my whole life," he said, adding that he could not believe that he now had to beg for charity care.

In the spring of 2006, one of Raymond's arms became numb from his fingertips to his elbow. Raymond could not afford medical care and decided to wait until his condition got worse and he would be able to go to a hospital emergency room for care.

A short time later, Raymond was admitted to charity hospice care. Raymond had always supported his family and was worried that his wife, a stay-at-home mother, would not be able to support their family.

Fortunately, friends and neighbors from the Waddells' community helped Raymond's wife get a job at the school that her children attended so she would be able to work and also be home when her children returned from school. She began to work while Raymond was in hospice, wanting to assure him that she would be able to support the family without him.

Not long after, Raymond died.

There is no doubt that Raymond's last months would have been less difficult for him and his family had he been able to afford necessary medicines and treatments instead of being forced to beg for care or go without.

PAMELA BELL

In the early 80s, Pamela Bell, a resident of Sheboygan Falls, Wis., in her early 30s, was diagnosed with a chronic musculoskeletal disorder called fibromyalgia, as well as emphysema and hepatitis C. Following her diagnoses, and despite increasing health problems, Pamela was able to work at a factory that developed equipment for the photograph processing industry. For a decade, health insurance offered at this job allowed her to address her own health care needs and also those of two sons and a sick husband who received SSDI and qualified for Medicare because he suffered from bipolar disorder and chronic back pain. When not working and caring for her family, Pamela pursued an interest in medicine by studying for a nursing degree.

Then, in the early summer of 2003, Pamela's health deteriorated dramatically: back pain from a childhood injury was making it difficult to walk and the muscle pain and fatigue from fibromyalgia was worsening. These problems affected Pamela's job performance, causing her to leave work early or miss entire days. In August of 2003, Pamela left her job because she could not physically continue to work and knew she would likely be terminated. In addition, she had to suspend progress toward her nursing degree.

Pamela was 40 years old when she applied for SSDI in December 2003, and while she and her husband waited for her case to be decided, they lived on his SSDI check of \$879 per month. Pamela lost her employer-based health insurance and was unable to pay the \$400-per-month premium required to continue insurance coverage through COBRA. At this point, the Bells could barely afford to buy food and pay other bills.

Pamela was worried by her increasing pain and fatigue. She began going to a low-cost clinic and saw a primary care physician and physiatrist (a doctor specializing in physical medicine and rehabilitation) who monitored her health and prescribed medications for fibromyalgia. The costs of these visits were low, but the Bells could not afford them, and Pamela soon had to cash her 401(k) of \$8,000, paying \$2,000 in penalties. The remaining \$6,000 was quickly spent, and soon after, she "let the bills pile up. There was nothing else to do."

Despite a critical shortage in funds, Pamela was able to fill most of her prescriptions for free or at low cost through pharmaceutical patient-assistance programs. At the time, she was taking an antiviral for hepatitis C, painkillers for fibromyalgia, and antidepressants to reduce stress related to her deteriorating health and dwindling finances. The Bells' increasing poverty also made them eligible for Medicaid, while they waited for Pamela's

SSDI determination. Medicaid coverage enabled Pamela to see a neurologist and pain management specialist. Before she received Medicaid coverage, Pamela's primary care physician had detected an irregular heartbeat that could not be investigated because of the lack of insurance. With Medicaid, she was able to see a cardiologist who ran tests and prescribed appropriate medication.

Pamela was denied SSDI. Persevering, she found a lawyer to represent her, and finally, in November 2004—11 months after first applying for SSDI—was deemed eligible for the benefit. In the winter of 2005, Pamela received her first SSDI check for \$764 and entered the Medicare 24-month waiting period. Social Security, recognizing that Pamela should have been approved earlier in the year, gave her a retroactive SSDI check and told her she would get Medicare in February 2006. Her new income put her just above the limit for Medicaid and she became uninsured again. She could continue seeing her primary care physician, pain management specialist, and cardiologist only because these doctors agreed to charge her a small amount or set up payment plans. Even with these special arrangements, Pamela could not afford to see her cardiologist every month as recommended. She saw him every six months instead.

Pamela continued to fill some of her prescriptions through patient-assistance programs, but also had to pay out-of-pocket for several medicines, costing her more than \$100 monthly.

While Pamela was in the waiting period, her muscle pain and fatigue worsened. She worried that she had not seen a specialist for hepatitis C. Instead, she had continued taking the antiviral medication that her primary care physician had prescribed, which lowered her immunity and caused her frequently to catch common illnesses. She was afraid that the hepatitis C was getting worse and causing irreversible liver damage.

Pamela spent most of the 24-month waiting period coping with her health problems and caring for her husband, which became increasingly difficult as she lost the ability to walk due to back pain and also became incontinent. She seldom left home and became increasingly depressed, but she could not treat the depression because she had been forced to stop seeing her psychologist when she lost Medicaid and had consequently not been able to refill her prescription for antidepressants. She had never been so anxious about her health.

In April 2005—almost two years after Pamela had become unable to work—the Bells were nearly out of money and Pamela was almost completely incapacitated by back

pain, muscle pain, and breathing problems related to emphysema. While her primary care physician tried to treat her as best he could, he could often do no more than prescribe narcotics to make her pain bearable. With no other options available to them, the Bells sold their family home and moved from Wisconsin to North Carolina with the help of a son who was serving there in the Marine Corps. Another son began to contribute \$800 each month; without this assistance, the Bells could not have paid their bills or for Pamela's medicine. Even with this assistance, the stress and pain were nearly unbearable. Pamela recalled that the worst aspect of waiting was "not being able to take care of yourself, and not being able to stop [the pain] from getting worse."

In February 2006, 24 months after Pamela would have received her first SSDI check if her case had been determined correctly, she became eligible for Medicare. Medicare covered a nebulizer that improved Pamela's breathing and helped control her emphysema. A specialist discovered that three discs in her back had deteriorated during the waiting period. Under Medicare, she could get a wheelchair, which she now needed to get around at home. The wheelchair allowed her to become more mobile and lead an active life again. She gained increased mobility after incontinence surgery, covered by Medicare, which also served to reduce her back pain.

With Medicare coverage, Pamela's health began to improve and she gained control over her life. She is now an active health care advocate and does volunteer work to collect mobility assistance devices, like wheelchairs, for several organizations that help disabled people. In February 2008, Pamela plans to compete for the title of Ms. Wheelchair North Carolina. She also hopes to realize her dream of becoming a nurse. Pamela was lucky that the herniated disks in her back did not lead to permanent incontinence and bladder problems. If her back pain had been treated sooner, she might not have become wheelchair dependent.

CHRIS RICHMEIER

Chris Richmeier was 41 years old and had worked in a Texas warehouse for nearly a decade when he was laid off from his job in 2004. He immediately began searching for a new one. At the same time, he began paying a monthly COBRA premium to extend his employee health insurance to his wife, Christine, and their two children.

A short time later, Chris's brother offered him a job at a home for delinquent boys that he had recently opened in Ohio. Chris and Christine decided that he should accept the job, bought a house, and moved to Ohio. Their children were happy and Chris loved his new work.

One February afternoon, a few months after the move, Chris picked up their 10-year-old son, Chaz, from his guitar lesson, and was driving home when his car collided with a car in front. Chris's car was knocked into the next lane of the highway where it was hit by two oncoming vehicles. Rescue workers had to cut Chris and Chaz from the burning vehicle before airlifting them by helicopter to a nearby hospital. Both Chris and Chaz had multiple fractures. Chris, suffering from a traumatic brain injury, was in a coma.

Chaz required two operations before he was released from the hospital. Chris's situation was much more grave. He remained unconscious over the next month and his doctors were not certain he would survive. The health insurance offered by Chris's new job had not yet begun, so the Richmeiers relied on their COBRA coverage, which covered much of Chris's and Chaz's medical care.

While Chris was unconscious, Christine applied for SSDI on his behalf. Social Security immediately approved Chris, who would begin to receive SSDI benefits that August and become eligible for Medicare two years later, in August 2007.

One month after the accident, Chris regained consciousness. He remained on a ventilator and was fed through a tube. At first, he could only blink one eye. He was unable to open the fingers of his left hand or uncurl his left foot. Chris's doctors prescribed roughly 10 medications in addition to physical therapy. They could not gauge the extent of brain damage but warned that Chris's recovery would depend upon the medical care he received.

During the next months, Chris was moved to a nursing home and then a rehabilitation facility. It was only through physical therapy that Chris gradually began to regain basic movements, like partially bending his arms and legs. As a result of the brain

damage, Chris had lost much of his short-term memory and had forgotten basic skills, such as how to eat and speak, which he had to relearn.

While Chris recovered, Christine realized that, in addition to household bills and medical expenses, the Richmeiers were paying \$1,300 a month for COBRA. She could not afford Chris's medical care without health insurance but, because of Chris's multiple injuries, private insurance companies would not insure him. Therefore, Christine felt she had no choice but to pay the COBRA premiums.

Then, Christine discovered that COBRA coverage expires after 18 months. Learning more, she found that Chris's disability actually allowed them to continue COBRA for 29 months. But even with this extension, the Richmeier's COBRA coverage, which they had begun to purchase when Chris was laid off in Texas, would expire in October 2006, nearly a year before Chris would become eligible for Medicare. Christine was shocked and horrified. "I flipped out," she recalled.

"It was always so stressful paying COBRA and then, constantly looming over us, that it would end. We didn't know how we could get ourselves afloat, let alone him," she said.

During Chris and Christine's 20-year marriage, Chris had handled the family's finances. Now, Christine struggled to pay for Chris's medical costs and their family's expenses. By the end of the spring, Christine had used most of their savings. She decided to sell their home in Ohio and move to a smaller, more-affordable one in Texas, near her family.

Still Christine could not afford their family's COBRA premium and decided to take the children and herself off the policy. Even so, Chris's premiums were expensive, at more than \$500 per month. Christine enrolled the children in the State Children's Health Insurance Program, a public health insurance program for low-income children, and she became uninsured. "I just try not to get sick," she said.

Stress caused by the family's finances and the approaching end of Chris's COBRA coverage began to take a physical toll on Christine who recalled, "I got a rash on my arm that would scab and itch, and cold sores, due to the stress of all this."

Before the Richmeiers moved back to Texas, Christine had Chris discharged from the rehabilitation facility where he was living. Chris, who was incontinent and still unable to walk, needed a lot of care and therapy. Home care seemed the best option until Chris could stay awake for more than three hours at a time. When this became possible,

Christine enrolled him in a more affordable day program that offered physical, speech, and cognitive therapy four days per week. His COBRA covered it in full, after a \$1,500 deductible was met.

With Chris in the day program, Christine got a part-time job as a crossing guard, which brought in a little income. But she could not consider full-time work. After the accident, Chaz had become extremely fearful of crowds and could not attend school; Christine had begun to home school him.

Chris struggled in the day program. At first, he could not stay awake for more than a few hours at a time. He found the day program's physical therapy exhausting and painful, often returning home in tears.

Christine remembers her husband as a jolly man. He was "so funny, always upbeat, smiling and joking," she said. In the group neuro-therapy sessions offered by the program, Chris was self-conscious and learned slowly. Christine was nonetheless extremely thankful for this care.

Chris's medical care remained difficult to afford. In addition to the day program's cost, Christine had to buy Chris supplies. For example, he needed custom-made braces because the accident had caused one of his feet to permanently point toward the ground and had stiffened his other ankle.

Chris's muscles remained stiff and inflexible. He still could not unclench the fingers of one hand, uncurl one foot, or rest his arms at his sides. Eventually, the COBRA coverage agreed to cover the surgical implantation of a baclofen pump that his doctor had recommended. The pump helped relax some of Chris's muscles.

Christine continued struggling to balance Chris's medical costs and their family's expenses. She began to spend Chris's IRA and then to charge expenses to credit cards.

"There are weeks I have to choose between his care and our food," Christine said. "We just buy macaroni."

The Richmeiers' church helped by bringing them food and, when their washing machine broke, replacing it. Christine was grateful, but also found the change in their lives, reflected by these acts of charity, difficult to comprehend. "We had a beautiful, custom-built house out in the country and now my kids get clothes from resale shops and ministries. We get meat once a month from the church. It's a big, big turnaround," she said.

In the fall of 2006, Chris's day program discontinued his neuro-therapy sessions because they felt he was no longer improving. Christine recalled, "I was really disappointed. I felt like they were giving up on him." Chris had begun to speak more at home and Christine felt that with therapy he would continue to improve. She attributed his poor performance in the program to his anxiety in the group setting. The day program continued to offer Chris physical therapy, and he continued to improve. He could now stand with assistance and sometimes take a few steps in place.

Christine persisted in trying to get Chris back into a neuro-therapy program. The day program referred him to a program at the University of North Texas, which provided therapy through supervised student-therapists. Christine was wary at first because it had a high student-therapist turnover. The program was affordable, however, so Chris entered it and rapidly began to improve with one-on-one attention.

The next month, in October 2006, Chris's COBRA coverage expired. Christine had already spent most of Chris's IRA and called multiple agencies and hotlines for additional assistance, to no avail. Finally, after extensive Internet research, she found the Texas Health Insurance Risk Pool. This health insurance, for uninsured state residents, offered limited health insurance after Christine met a \$1,000 deductible and then paid 20 percent of the next \$3,000 of medical costs.

Without any other options, Christine was grateful for this health insurance. She contacted representatives of the program, none of whom could tell her if the health insurance would cover Chris's therapy and, if it did, how much she would have to pay out-of-pocket. Instead, she would have to wait to find out until she had paid Chris's deductible and then submitted his first claim. If this claim was rejected, Christine would be responsible for the entire cost of Chris's therapy. Christine had no choice but to take this risk.

Chris and Christine look forward to August 2007 when Chris will finally become eligible for Medicare. Christine has spoken with several caseworkers who have told her about various programs Chris will qualify for—and be able to afford—once he has Medicare. Christine is very hopeful that Medicare will reduce Chris's medical costs. Until then, she said, "I don't really know. We just kind of make it through. I'm still always praying that I'm making the right decisions."

RICHARD SCHADT

Richard Schadt suffered from polio as a child but ultimately recovered, except for a limp. At 14, he got his first job as a meat cutter; just a few years later, he used his savings to put himself through college, where he earned a business degree. Over the next three decades, Richard married his wife, Peggy, and raised five sons and a daughter while working for several major food chains. As his career grew, Richard organized and spoke at marketing conventions, advancing to senior vice president of perishables for a supermarket chain. Over the years, Richard gave charitably whenever possible: every Thanksgiving, he helped distribute turkeys to thousands of poor families in his community.

In his early 50s, with three children still living at home (one disabled and needing special care), Richard decided that he had saved enough to retire. He and his family moved to Stella, N.C., where they built a house. Wanting to remain active during retirement and feeling financially stable, Richard opened a small grocery store.

Soon after these events, Richard began to suffer from flu-like symptoms. He paid little attention, continuing to pursue his usual activities until he suddenly collapsed one day at work. His doctor diagnosed him with post-polio syndrome, a degenerative condition that sometimes affects people who have had polio as children. Post-polio syndrome weakens muscles and causes fatigue. There is no treatment except to try to slow or stop its progression. Richard's condition was severe and his doctor gave him six years to live. The Schadt family had health insurance through Richard's business, but the copays for his frequent doctor visits and medications were difficult to afford. His prognosis was poor, all his doctors recommended he apply for SSDI.

Despite documented support from Richard's doctors, he was not approved for SSDI until two-and-a-half years later, in 1997, and only after he had hired a lawyer to help with his case. During this time, Richard and Peggy quickly depleted most of their savings to meet the costs of Richard's health care and the needs of the family. Richard and Peggy could no longer afford to pay college tuition for their three older children who took out loans instead.

Richard began to experience constant pain in his joints as his muscles deteriorated. He was unable to work. When a large supermarket opened nearby, Peggy—now managing the business while dealing with Richard's health problems—found she could not compete. The Schadts declared bankruptcy and their grocery store was leveled. With the store went the Schadt family health insurance.

Richard's prescriptions now cost nearly \$1,600 per month, and his condition was worsening. For a while, Richard and Peggy were able to pay the high COBRA premiums necessary to maintain their health insurance coverage, but they soon became too expensive. Peggy began to look for work that might provide health insurance. The family was uninsured for nearly six months before Peggy found a job and completed her health insurance eligibility period. During this time the Schadts had to pay the full cost of Richard's prescriptions and doctors' visits. Peggy worked the graveyard shift so that she could care for her husband and their disabled son during the day.

Richard was approved for SSDI in 1997; because he had always earned a good salary he was awarded \$2,000 per month. The money was barely enough to pay for his medicine and doctors copays, yet it was high enough to put the family above the income limits for state assistance programs.

Richard had always been the family breadwinner and was unwilling to take charity. Despite his pride, Peggy wrote to drug companies to beg for help getting Richard's drugs. "The drug companies would not even lower the payments for his drugs. There was no compassion. They did not care that we could not buy food," Peggy said.

In the late 90s, when Richard and his family were trying to navigate these difficulties, very little was known about post-polio syndrome. The two clinics that treated this condition were far away. Unable to access this expert care, Richard was treated by his primary care physician who did not know much about post-polio syndrome and who, Peggy said, "was learning along with him."

While Richard waited to get Medicare he began to lose movement in his muscles and had difficulty even picking up a pen. He experienced constant joint pain but could not afford braces to control the pain and prevent further deterioration. Instead, Richard and his doctor experimented with different types and doses of medicine. This strategy worked for short periods but failed as soon as Richard's body became used to increased dosages of the pain medications.

By 1999, Peggy remembers feeling constant stress about how to cover the cost of meals, in addition to Richard's medical needs. Richard had cashed part of his 401(k) retirement fund to cover expenses, but Peggy still had to work long hours. Richard, accustomed to being the family provider, began to struggle with depression.

“We went from affluence to zero. We were destitute,” said Peggy. She is still appalled they received no assistance. “The government didn’t work for us, and he had always worked hard and had paid taxes. They failed us in every way,” she said.

The medical and financial difficulties put strains on the marriage. In 1999, Richard declared personal bankruptcy. The family home was foreclosed and Peggy moved with their youngest children to New York to be near her family. Richard felt he could not leave his doctor, so he stayed in North Carolina where his brother lived. The family lost their health insurance again after Peggy left her job.

“Not only was I destitute, but technically homeless as well,” she said. Peggy and the children moved in with her mother who supported them for a few months. The family was uninsured for five months while Peggy found a job and waited for her employer-based health coverage to begin. Richard cashed the rest of his 401(k) to pay for medical expenses and used the little money he had left to buy a trailer. Peggy spoke with him often and said he was “weak and frail.” “He had lost everything that he had worked for,” she said.

Richard finally got Medicare in late 1999, but Peggy felt it was too late. “He had given up,” she said. Four-and-a-half years after first applying for SSDI, his muscles had atrophied and he needed a cane and walker to move. He was depressed and began drinking heavily.

Medicare became Richard’s primary insurance, supplemented by Peggy’s coverage. Peggy estimated that, “[Medicare] saved him thousands on drugs, hospitalizations, and doctor visits.” For the first time, they were not scraping by, forced to choose between food and health care.

During the years that followed, the quantity of pain killers Richard needed steadily increased until he was taking 750 milligrams of morphine three times per day. In 2005 he was hospitalized, and Medicare and his supplemental insurance picked up most of the cost. In early April 2005, Richard’s gall bladder ruptured and he was hospitalized again. During the next six weeks he battled an infection and was placed on life support. On May 19, 2005, with his daughter, Kim, by his bedside, Richard died. His family buried him six days later, on what would have been his 59th birthday.

Peggy and the children have moved forward with their lives, yet they still feel the effects of this tragic time. Peggy is finally out of debt. She and the older children, who had

applied for college loans, had been forced to take out high-interest loans because of Richard's bankruptcy and short debt history. Despite such setbacks, Peggy said the children, "[have been] resourceful and [done] what they had to do." They have gone on to a variety of professions. Peggy is very proud of them.

Shadows still fall on Peggy's mind when she recalls her husband's experience. "He always paid taxes, but when he needed the system, it wasn't there for him. Dick never even had the chance to retire. He worked all of those years for nothing," she said. She does not know if having more care and avoiding financial stress would have affected Richard's condition, but she suspects it would have. She is certain, at any rate, it would have made his final years easier. "Words can not explain how much we lost," she said. "It was enough to destroy our family."

ELAINE GILBERTSON

In December 2003, Elaine Gilbertson traveled from her home in Overland Park, Kan., to South Dakota to spend the holidays with her brother and his family. On Christmas Day, Elaine, 57 years old, had a stroke at her sister-in-law's home and was rushed to a nearby hospital. The stroke was severe and she sustained extensive brain damage. Coupled with a loss of movement in her right hand and right leg, it was now impossible for Elaine to walk, talk, or even feed herself. Following the stroke, Elaine's doctor examined her and determined the stroke had likely been a result of changes in her vascular system owing to diabetes.

It was not clear how quickly, or to what extent, Elaine would recover. She was employed as a project assistant at a pharmaceutical-testing company, but because it was clear she could not immediately return to work, Elaine's sister-in-law applied for SSDI on her behalf. In the meantime, Elaine began the 90 days of fully paid short-term disability her employer offered.

Thanks to good hospital treatment for three weeks following her stroke, Elaine recovered enough to be moved from the South Dakota hospital to one in Overland Park, where she stayed for three weeks, and then to a rehabilitation facility near her home.

Back in Kansas, Elaine continued to receive the rehabilitative services that she started in the hospital, including physical, occupational, and speech therapy five days per week. Slowly, she learned to speak with limitations and to walk with a cane. She also regained writing skills, which were especially challenging because she was right-handed and no longer had the use of her right hand. Though paralysis in her right arm and numbness in her right leg did not improve, Elaine was well enough to return home in April 2004.

By the time Elaine returned home, her short-term disability insurance had ended and the long-term disability insurance offered by her former employer had begun, through which she will receive \$350 per month until she turns 65. Elaine had no other income, but needed to pay \$500 per month to continue her health insurance through COBRA. Elaine relied on savings to pay this and other costs. In addition, because her insurance did not cover the assisted living facility where she had lived for two-and-a-half months, she was forced to pay roughly \$10,000 out-of-pocket, depleting nearly one-third of her savings.

In June 2004, Elaine was approved for SSDI. Social Security recognized that Elaine should have been approved earlier in the year, so she did not have to wait the usual

five months to begin receiving benefits. She began receiving \$1,200 per month in July. Elaine's rent, for a small first-floor apartment, was nearly \$700 per month. Together with her COBRA payments, it was difficult to make ends meet. Despite the financial stress, COBRA payments allowed Elaine to continue receiving physical, occupational, and speech therapy. Because she could not drive, members of her church drove her to therapy and doctors' appointments.

By January 2005, just a year after the stroke, Elaine was still frail and had not regained much mobility. She had lost the ability to play piano, crochet, and participate in other activities she enjoyed. Elaine had been an excellent cook, but the stroke had destroyed her sense of taste. With few hobbies to divert her, Elaine passed the time by worrying. She had used most of her savings to pay bills and worried she would not be able to continue paying them. Before the stroke, Elaine had been independent and self-sufficient. Now she was struggling with a depression so severe she tried to commit suicide. "I had given up," she said. "Why should I live? I didn't see any reason why I should live."

Elaine took 150 pills, but then called a friend who took her to the hospital. She was in the intensive care unit for three days and in the hospital for 10 more. COBRA covered most of the hospital bill.

Afterward, Elaine began going to a psychiatrist and continued physical, occupational, and speech therapy, and had Botox injections in her right arm to help regain movement.

In February, Elaine discovered that she lived near the American Stroke Foundation. To stay active, she began to volunteer there teaching computer classes. This activity plus psychiatric therapy made her somewhat happier. In October 2005, Elaine's COBRA health insurance reached its 18-month limit. COBRA can be extended to 29 months for people with SSDI. Elaine asked her health insurer for this extension but was told she should have requested it when she first began COBRA. Because she had failed to make this request—which she had not been aware she needed to make—her insurer refused to grant the extension, and Elaine was left uninsured. "I would have needed to apply for [the extension] while I was recovering from the stroke and I didn't know that. They didn't tell me," she said.

Some of Elaine's friends wrote letters requesting that COBRA make an exception and extend her coverage, describing her poor health and need for medical care. These letters never received a response.

Elaine was terrified at the prospect of being uninsured for the eight months before becoming eligible for Medicare. Her condition was improving slowly, and she was afraid that an interruption in her therapy might permanently damage her recovery. After extensive online research, Elaine found a limited health insurance policy that she bought as a safety net. Because the policy did not cover doctors' appointments, she began to visit doctors as infrequently as possible. For example, she was supposed to go to an ophthalmologist who could monitor how diabetes was affecting her eyes, but she could not afford it.

During this time, Elaine was able to fill her prescriptions through a mail-order pharmacy. She spent around \$400 per month on drugs. However, she could not afford to continue physical, occupational, or speech therapy, or to receive additional Botox injections, which were visibly improving her manual dexterity. As an alternative, she received physical therapy from the American Stroke Foundation, where she was volunteering. For a short time she also received speech therapy there, but the Foundation's case load was large and it had to take care of people with greater impediments first. Even though Elaine's speech was difficult to understand, it was intelligible, and the Foundation had no choice but to discontinue speech assistance to her.

In June 2006, Elaine became eligible for Medicare. During the time between having the stroke and receiving Medicare coverage, she lost 140 pounds, which she attributes to anxiety. Because her Botox treatments had been suspended, she also gave up the progress she had been making toward mobility in her right arm. She still walked with a cane. Overall, Elaine still feels frail and physically vulnerable. "I am always so afraid that I'm going to fall. I walk very carefully," she said. Elaine believes her speech and movement would have improved more with uninterrupted physical, occupational, and speech therapy.

Of her current health and financial situation, Elaine said, "Medicare covers a lot." She sees her primary care physician and an ophthalmologist when necessary. She is grateful to have received preventive services like a mammogram, and has enrolled in a Medicare drug plan that has significantly lowered the cost of her prescriptions. Elaine was surprised to learn that Medicare covers physical, occupational, and speech therapy. She plans to take advantage of these benefits soon so she can remain an active member of her church and perhaps begin to pursue the other hobbies that were important to her before she became disabled. If she had been covered by Medicare, she might have received uninterrupted physical, occupational, and speech therapy that might have allowed her to recover more fully. For Elaine, the 24-month waiting period had a destructive impact on quality of life and, most likely, on the degree of her long-term disability.

ROY MAUEL

Roy Mauel and his wife, Shirley, lived in Delavan, Wis., and worked at a factory that produced and assembled silicone parts for computers, printers, and other electronic equipment. They were tied to their community and in the process of buying a house. At work, Roy usually set up and tested the equipment. At the end of a late-night shift in the spring of 2002, when he was 45 years old, Roy was standing on a hydraulic platform making last-minute adjustments to a product. Turning around, he slipped on oily residue and fell off the platform. His foot caught between two support ribs and was twisted 90 degrees.

An ambulance took Roy to the hospital where, a few hours later, a surgeon operated and put a cast on his leg. During the next two days, doctors monitored Roy's health and released him from the hospital. Workers' compensation insurance covered his hospital stay.

Once home, Roy began physical therapy. He also began to see a pain management specialist who prescribed four different medications. An orthopedist diagnosed him with reflex sympathetic dystrophy, a pain syndrome that often affects limbs after a serious injury, and warned Roy that the nerves in his leg had been severely and permanently damaged. Despite these opinions, Roy was confident he would return to work soon.

In the meantime, Roy began to collect total temporary disability from his job, of about \$1,600 per month, as well as worker's compensation, which covered the costs of medical services and medications. Roy's employer gave him small odd jobs so he could maintain his employer-based health insurance.

Despite this help, the Mauels could not afford daily transportation for Roy to and from doctors' appointments, nor could they afford health care costs or regular household expenses. The Mauels' income dropped considerably when Roy stopped working regularly and their scant savings quickly evaporated. Roy and Shirley began to use credit cards to pay for food and medical costs. By 2003, they had accrued so much debt they were forced to declare bankruptcy.

In the summer, Roy's pain management specialist gave the Mauels more bad news: Roy's injury had reached a "plateau" and would not improve. As he was still experiencing near-unbearable pain and having difficulty walking, Roy knew he would not be able to return to a manual job. In an effort to help him regain some lost income, the pain management specialist contacted a state rehabilitation doctor, who recommended Roy apply for SSDI.

In November 2003, before Roy had applied for SSDI, he succumbed to pneumonia. His doctor prescribed antibiotics that quickly cured him, but at a follow-up visit, doctors spotted a lump in his lung. A biopsy proved the lump was a malignant tumor that could not be operated on because it was wrapped around a major artery.

The doctor prescribed immediate radiation treatments and chemotherapy. The cancer diagnosis convinced Roy he could not return to work. He applied for SSDI and was quickly approved.

Until this time, Roy's employer had managed to keep him insured. But now, before Roy could begin receiving cancer treatments, the company was sold, and neither Roy nor Shirley was rehired. They became uninsured, except for Roy's workers' compensation which only covered physical therapy, pain management, and prescription drugs related to his foot injury. Roy would not get Medicare until October 2005. By this time, the total temporary disability Roy received had decreased to \$900 per month. The Mauels, still reeling from their declaration of bankruptcy, could not afford to continue their employer health insurance through COBRA, which would have cost more than \$900 per month.

The Mauels could not afford Roy's cancer treatments, but without them he would die. Roy was desperate and spoke with doctors at a nearby hospital. The hospital applied for Medicaid on Roy's behalf, but the Mauels' income was too high and they did not qualify for the full benefit. He was, however, eligible for Medicaid through a spend-down, which meant he would have to spend a significant amount on health care costs each month before Medicaid would cover the month's remaining expenses. Roy could not afford to meet his Medicaid spend-down and the hospital agreed to write off the spend-down amount as charity care.

His spend-down paid, Roy became fully covered by Medicaid. In addition to covering his cancer treatments, it paid for the six medications he was prescribed to build his immunity, counter the cancer medication side effects, and treat blood clots caused by the chemotherapy. The treatment was difficult, but Roy was thankful to receive it.

That spring, Roy started getting SSDI checks of \$1,000 per month. As his chemotherapy and radiation treatments ended, he began receiving hospital bills, though he believed his expenses had been paid through the hospital's charity and Medicaid. Roy was confused and called the hospital's billing department, which informed him that the bills were for the amount he had to spend down each month in order to get Medicaid coverage.

Roy spoke with the doctors who had told him the treatment would be written off as charity care. They insisted this was still the case. The billing department, however, told Roy that his doctors could not make this decision. “It was like pulling a tooth,” Roy said. “On one end they say they’re not charging and on the other they are.”

The hospital’s billing department began to call the Mauels repeatedly, demanding they pay the bills and threatening to end his care if they did not. The Mauels were trying to make ends meet every month and could not pay these bills, which totaled about \$30,000. Though he had been warned to stop receiving hospital care, Roy continued to see his oncologist, who wanted to ensure the cancer did not recur.

Continuing calls from the hospital left Roy fearful. “It was not like someone talking to another person,” Roy said. “It was like someone cutting you down because you couldn’t pay.” In the end, Roy began to ignore the phone calls, though he was very worried that the hospital would cut off his medical services.

Finally, the hospital’s billing office worked out a payment plan: Roy had to pay \$25 for every service received. While this seemed like a good plan, Roy soon realized that it meant he would rack up multiple charges every day—an average of sixty bills every month totaling around \$1,500. Again, Roy found he could not pay his medical bills. His cancer had not returned, but he still felt the effects of the chemotherapy drugs, including a tingling in his fingers and a weakness in his extremities that made walking even harder.

At the end of 2004, roughly a year after Roy’s cancer diagnosis and almost three years after his initial injury, the hospital sent a collection agency after the Mauels. But Roy was no longer scared. “We had nothing to take anymore,” he said. Roy did not even look at the total bill, though a glance showed him it was six digits. After the threatening communication from the collection agency, Roy was forced to stop seeing his oncologist for follow-up care. He only saw his pain management specialist every three months for his foot. Although workers’ compensation had covered these costs, it began to deny the claims and mail the bills to Roy, claiming he had recovered from his injury and no longer qualified for care. “All of a sudden they just pulled the plug,” Roy said, even though he still had excruciating pain in his foot and ankle.

Throughout this period, workers’ compensation continued to pay for prescriptions to treat the pain and disability in Roy’s foot and leg. He was able to fill his cancer medication prescriptions for free or at a low cost through patient-assistance programs established by pharmaceutical companies. Then, Roy’s vision began to decline, and he

could not afford to see an ophthalmologist or buy glasses. He also developed an ear infection but put off going to the doctor until it had become severe. Even then, Roy could receive care only because the doctor agreed not to charge.

In October 2005, Roy finally got Medicare. For the first time in a year he saw his oncologist and learned the cancer had not recurred. Medicare covered the appointments with his pain management specialist, and he could finally stop worrying that workers' compensation would stop covering these appointments and the treatments to alleviate his pain.

Today, Roy is grateful he can afford his health care. "It feels like everything with Medicare gets me a discount," he said. Roy also appreciates that he does not have to fight a billing department to get care and wonder at every step whether he will win. "It makes me feel better. At least there's something to cover me," he said.

Despite this alleviation of stress, however, Roy still has outstanding bills from the Medicare waiting period. The hospital that treated his cancer has been sued for overcharging uninsured patients, and Roy hopes that one day his hospital bill might be waived. Until then, collection agencies continue to hound the Mauels. Shirley was able to eventually find work, but her job does not offer employer health coverage and she remains uninsured. By the time Roy got Medicare, the couple was so behind on their house payments that they decided to sell the home they had saved so long to buy and to move to a small apartment.

DARLA POLASEK

Darla Polasek and her husband were living in La Grange, Texas. One of their sons lived nearby with his family; the other was in the U.S. Navy and traveled around the world. Darla, age 40, had been working seasonally, preparing tax returns for several professional services companies. In the winter of 2003, wanting more, she interviewed for a full-time job.

On an evening soon after a job interview, Darla was riding on the back of her husband's motorcycle when he tried to pass another motorcycle and lost control. Darla was thrown, hit a sign by the side of the road, and lost consciousness.

She awoke in the hospital, having been given CPR three times before reviving. She learned the accident had broken many bones, damaged the nerves in one thigh, and punctured her left lung. As a result, most of her body was encased in casts or bandages, and her pelvis had been smashed and was being held together by a long pin.

Three weeks later, Darla's body began to heal and she was transferred to a rehabilitative hospital where she could be treated by specialists. Her doctors prescribed physical therapy and a variety of medications that Darla was able to pay for under her husband's employer-based health insurance. While Darla was in the hospital, the company at which she had interviewed offered her a job, but she was forced to turn it down.

After six weeks, Darla was discharged from the rehabilitative hospital, but her tendons and muscles—especially in her back and pelvis—continued to hurt. She received physical therapy at home and began water therapy. She continued to see several specialists, along with her primary care physician, and took more than 15 medications, including pain killers, muscle relaxers, and medicine for a thyroid condition.

It soon became clear that Darla's injuries were not healing well. Her pelvic muscles were so damaged that she often had to wear a diaper. As a result of the accident and subsequent immobility, muscles throughout her body became painful, making it difficult to walk. Her back pain was so severe that she could sit only for short periods and with a cushion. Soon, Darla also realized that her memory had been affected by the accident and she could not retain details for more than a day or two. She resigned herself to not returning to work.

Meanwhile, Darla's marriage, strained before the accident, fell apart. She and her husband divorced and she lost his employer-based coverage. By this time, Darla had used

most of her savings to pay her medical bills. She could not afford private health insurance premiums, as her serious health problems made the already high rates even higher. In August 2004, at age 40, Darla applied for SSDI. Social Security found that Darla became disabled in December 2003, so she received benefits retroactive to April 2004. Her monthly check was \$933 per month, but she would not get Medicare until spring 2006.

At this point, Darla could not afford her medical care, given her status as a single person. Having stopped going to specialists and discontinued water therapy, she received care only from her primary care physician, who did not have the expertise to treat her injuries but could prescribe medications. Darla could only afford a visit to the doctor if she did not buy thyroid medicine the month before or after each visit.

Darla adjusted her lifestyle to pay for medical and household necessities. She moved into a low-income apartment, which was burglarized twice during the next year-and-a-half. She lowered expenses by conserving electricity and eating less; one pot of spaghetti could last her a week. “I understand what people mean when they say they have to choose between food and medicine,” she said.

Even with these sacrifices, Darla could not afford her medicine. When she had been covered by her husband’s health insurance, she had used prescription patches to ease back pain. But each pack of patches, which she had to buy twice a month, cost \$180. She could not afford them, so her primary care physician prescribed oral pain killers instead. He thought Darla needed a back operation, but could not make a diagnosis without a CAT scan, which she could not afford.

The pain killers failed to combat Darla’s back pain sufficiently to allow her to sleep through the night, even with sleeping pills. She had increasing trouble walking and began to need a cane most of the time. Many days, she did not have the energy to leave home. When she did feel well enough, she enjoyed seeing her family—especially her granddaughter, reading, and going to church.

Midway through the waiting period, Darla discovered her county offered limited health coverage through a clinic to uninsured people. “I had to fight, and pretty darn well beg, for every piece of information for help on things that applied to me,” she said.

Darla continued to see the primary care physician who was familiar with her case, but now she could receive some treatment at the clinic as well. While this care was welcome, there were obstacles: Darla had to wait hours at the clinic before being seen by

doctors, usually for no more than 15 minutes. While the county assistance helped lower the cost of some prescriptions, it did not cover all her prescriptions, including the patches she used to combat back pain.

Then, worse news arrived. After suffering a fall at home, Darla was taken to the hospital, where a doctor told her that her liver had been damaged by the high quantities of pain killers. Then, in the spring of 2006, a sheriff arrived at Darla's home and announced that a doctor's office was suing her over an unpaid bill from a medical procedure. Darla had been paying off the bill but could not afford to continue her payments after the accident. She had contacted the hospital's billing department, which told her that she did not have to continue paying the bill.

When the sheriff arrived, Darla said, "I didn't know why he was coming. Then, when he handed me the paperwork, I just didn't know what to do. I was scared. I thought they might take me to jail over it," she said.

Darla—with just \$10 in the bank to last the rest of the month—was told she had to pay the bill. If she did not, any money deposited into her account would be seized, including the monthly SSDI check Darla needed to survive.

The Medicare Rights Center helped Darla find a pro bono lawyer who told her the collection agency's threats were meaningless: they could not legally seize her SSDI check. However, the collection agency attempted to get a judgment against her, ordering her to pay the money owed. A hearing was scheduled in Dallas. Darla could not afford to hire a lawyer to represent her or even the transportation to Dallas. The judge issued a judgment by default, because she failed to appear. As a result, the collection agency was permitted to collect any money deposited in her account, except for her SSDI payments. "I want to go to work. I don't want to live like this," Darla said. "I was raised that you pay your bills."

In May 2006, Darla finally got Medicare. She qualified for a program that paid her monthly Part B premium and, with the help of the Medicare Rights Center, for Extra Help, a federal program that significantly lowered her prescription drug costs. Darla hopes that with the care of specialists she can regain a normal life.

LAUREN KOWALCZEWSKI

Lauren Kowalczewski lived in Wyoming, Mich., where she was a senior billing clerk at a transportation company. She lost most of her hearing at a young age but her disability did not prevent her from working. In fact, her willingness to put in long hours quickly led to new responsibilities and promotions at her company. She bought a house and felt that she was getting ahead. By the summer of 2001, when she was in her early 50s, Lauren felt she was ready for the next step in her career and applied for a job at another transportation company.

While waiting to hear if she would be hired, Lauren noticed she often felt faint during the day. When she went to the doctor for a checkup, he discovered blood clots in her lung and leg and also found her to be anemic with a low blood count. Lauren spent the following eight days in the hospital to receive blood transfusions and take various tests. While there, the company at which she had applied for a job called to arrange an interview. Because further tests found no additional health problems, doctors prescribed blood thinners and released her from the hospital. Lauren interviewed for the new job, was hired, and began working in August.

In January 2002, Lauren's job was going well and her health was so stable that her doctor replaced her blood thinner with a daily aspirin. But in April, nine months after she had begun her new job, Lauren began to feel faint again. Since her hospitalization, she had had blood work done every other week, and that week's tests revealed she was anemic, with an extremely low blood count. Lauren's doctor immediately admitted her to the hospital for more tests and blood transfusions. In the hospital, doctors discovered that stomach ulcers had led to the blood loss and anemia. Hospital tests also revealed that Lauren had a benign stomach tumor, as well as diabetes. Lauren had not worked at her new job long enough to take more sick time, but she could not be discharged from the hospital. As a result, she was fired, but her employer provided her with 12 weeks of short-term disability, which covered most of the medical tests and an operation to remove the stomach tumor.

Still recovering and unable to work, Lauren applied and was quickly approved for SSDI. She soon realized that health insurance was not part of the deal. "I remember I was shocked to find out that I had to wait two years! All I could think was 'How in the world can they make me wait two years for health insurance when it's my health that got me here in the first place?'" she said. Lauren was already paying high monthly premiums to continue her employer health coverage through COBRA. Her only income now was a

small SSDI check, and her medical bills, combined with other bills, quickly depleted most of her savings. She was forced to drop COBRA, losing all health coverage, and to cash in her life insurance policy.

Without health insurance, Lauren got her prescriptions filled through patient assistance programs, saw doctors at free clinics, and as she said, “tried hard not to get sick.” She had worked long enough that her SSDI checks put her above the limit for most federal low-income programs that could have helped her. She was given a Medicaid spend-down of just over \$700, which meant that only if her medical costs became greater than \$700 during a given month would Medicaid pick up the remaining expenses.

Lauren was able to get by without significant debt until the end of June 2003, when she began to feel exhausted, became extremely dehydrated, and developed an intense pain in her left side. She waited a few days, but as her condition worsened she had no choice but to see a doctor. The doctor suspected that Lauren had a kidney infection and gave her an antibiotic. Two days later, she felt worse and went to the hospital. Tests confirmed she had a kidney infection, and, as a result of diabetes, blood glucose well above the normal level. Though her hospital stay lasted only a few days, it spanned the end of June and beginning of July, requiring that she meet her Medicaid spend-down twice—once for each month she was in the hospital. Consequently, Lauren received over \$1,400 in hospital bills. Without any savings or excess income, she was forced to pay her medical bills with money she had put aside to pay her property taxes.

Lauren got Medicare in 2003 and can now see her doctors at any time and pay for needed medications. If she is hospitalized, Medicare will pay a significant portion of the cost. Yet the relief of getting Medicare is overshadowed for Lauren by the consequences she now faces as a result of having been uninsured. “I had savings, my life insurance, good medical insurance, and was getting ahead of everything. I’m just getting by on my income now. If I had Medicare at that time, it would have been wonderful. I didn’t, so I’m living with that,” she said. Lauren is still trying to make her meager SSDI check cover not only her immediate needs but also back-tax payments and other bills accrued during the 24-month waiting period. For Lauren, the net effect of the Medicare waiting period was a loss of financial security, which posed difficult challenges for her future.

DENNIS HYDER

Dennis Hyder worked at a textile manufacturing plant in rural Kings Mountain, N.C., where he created the cloth patterns produced by the plant. In his spare time, Dennis attended church and went fishing with his daughter, Amber.

In the summer of 2004, when Dennis was in his late 40s, he began to have trouble breathing, prompting a visit his doctor. The doctor ran a variety of tests, including an X-ray of Dennis's lungs. Dennis was immediately diagnosed with emphysema, an irreversible lung disease, and given a breathing treatment. The doctor referred Dennis to a specialist and prescribed several medications and inhalers.

Dennis's doctor believed that a primary cause of his emphysema was the textile manufacturing plant. At his job, Dennis worked closely with machines that wove flax into cloth; a thick cloud of flax hung in the air at all times. The inhalation of flax particles has been linked to an increased risk of emphysema.

Following his diagnosis, Dennis visited a specialist who discovered his lungs were functioning at less than 20 percent of normal. The specialist told Dennis that he would need a lung transplant and advised him to stop working and apply SSDI.

Dennis had not planned to retire so early. He did not have much savings and, despite his increasing trouble breathing, decided to continue working. In August, Dennis notified his plant manager of his diagnosis; a few weeks later he was laid off due to plant "downsizing." Dennis had no choice but to follow his doctor's advice: in September he applied for SSDI.

Dennis learned that he could continue his employer health insurance through COBRA, but his premium alone would be \$552 per month. Dennis's wife was a substitute daycare teacher and her job did not offer health insurance. With Dennis unemployed, the Hyderys' only income was Dennis's wife's salary. The Hyderys had limited savings and could not afford to purchase COBRA coverage for the entire family.

Dennis began to contact other health insurance companies to find an affordable option. Each company told Dennis that it would not insure him because he was so sick; one representative described Dennis as "uninsurable."

Dennis could not afford to fill his prescriptions or see a specialist without health insurance, so the Hyderys purchased COBRA health insurance for his care. Dennis's wife

and 13-year-old daughter became uninsured. The following year, Dennis learned about North Carolina Health Choice, a state program that provides health insurance for children, and he enrolled his daughter.

In addition to paying COBRA premiums, Dennis was required to pay the first \$1,000 of medical costs out-of-pocket, as a deductible, and 20 percent coinsurance thereafter. Even though he was quickly approved for SSDI benefits, he would not receive his first SSDI check until March 2005 and would not become eligible for Medicare until March 2007. He was saddled with health care costs that were extremely difficult to afford.

Dennis began to worry that he and his wife could not cover their regular household expenses and his medical costs, which included medicine, inhalers, and rehabilitation services three times each week. The Hyders recognized they would not be able to go on their annual family vacation and would need to make major lifestyle changes.

Even after the Hyders reduced their household expenditures, Dennis's health care was unaffordable. To help defray costs, Dennis asked his doctor for free medicine samples. He explained his financial situation to the rehabilitation hospital, which agreed to give him charity care. For Dennis, asking for help was difficult. "You have to swallow your pride. You've worked all your life and now you're asking for charity," he said.

The Hyders were forced to borrow money from family members. They hoped to begin repaying this money when Dennis began receiving SSDI benefits. But the \$1,500-per-month barely covered his medical costs, making it difficult for him to meet his obligations.

Meanwhile, Dennis's specialist wrote several letters to Duke University Medical Center, which has a lung transplant program. In the late spring of 2005, Duke arranged for Dennis to be evaluated.

In June, the Duke doctors ran various tests on Dennis. He also met with a financial coordinator who told Dennis that while Medicare would cover many of the costs related to a lung transplant, Dennis's current health insurance would provide only partial coverage. Dennis could not afford to pay for a transplant and Duke would not consider him for a transplant without a guarantee of payment. The financial coordinator at Duke University Hospital recommended Dennis try to raise the money needed for a transplant.

Dennis's health had continued to decline. Breathing had become increasingly difficult and often painful. But Dennis and his wife did not despair. Upon returning from Duke, they began to raise funds. With the help of Dennis's church, family, and friends, he

was able to raise money through candy sales, hot dog stands, auctions, and a Web site. In the course of a year, the Hyders raised more than \$10,000.

In the spring of 2006, Duke asked Dennis to move to an apartment in Durham, near the hospital, and enter the transplant preparation program. Dennis paid for the apartment and the program through his fund-raising efforts, and the family moved.

Before moving, Dennis created a committee of friends and church members who continued to raise funds on his behalf while he prepared for the transplant. Dennis depended on this money to pay his coinsurance and the medical costs his health insurance did not cover. When necessary, he also used these funds to pay his COBRA premium.

In August 2006, shortly after completing Duke's pre-transplant program, Dennis received a lung transplant. Following the operation, he remained in the hospital for nearly a week, and then continued living in nearby apartment to receive follow-up care. He was prescribed roughly 50 medications and was fed through a tube in his stomach.

A week after the transplant, Dennis began to have trouble swallowing. After a few weeks he had lost 25 pounds and could not even swallow water. Dennis was readmitted to Duke, where doctors discovered the operation had resulted in neurological damage. He was hospitalized for a short time and then discharged.

Over the ensuing months, Dennis was hospitalized several more times for various infections and blood clots. Again, the money raised on Dennis's behalf covered these medical costs. Without it, Dennis would have accumulated major debt. In December 2006, he was finally well enough to return home.

Dennis's chest is still sore and he has a scar that runs from one armpit to the other. He was recently hospitalized because his feeding tube became infected and had to be removed. After this procedure, Dennis began to take his 50 medications orally. Dennis will take many of these medicines for the rest of his life. He will also return to Duke University Medical Center for periodic checkups.

Since Dennis's transplant, he has developed diabetes, adding to his health care costs. Dennis has not yet been billed for the lung transplant or subsequent multiple hospitalizations. He knows he will be responsible for at least 20 percent of roughly \$300,000 in costs for the transplant and hospitalization.

“We’re still fund-raising because when those bills come in, we’re expecting to pay 20 percent, ” he said “I still worry that we’re not going to raise enough money. If I don’t have it I’ll just pay them \$5 a month. That’s all you can do.”

Dennis became eligible for Medicare in March 2007. “I’m glad it’s finally started,” he said. Meanwhile, Dennis’s wife remains uninsured, and Amber continues to be covered by the state health insurance program.

Dennis will be relieved when he no longer has to pay an expensive COBRA premium or depend on the kindness of others. He hopes that his health will continue to improve and that he can work his way through his bills. Dennis hopes one day to be able to raise funds for others, like himself, who have nowhere else to turn.

MARK WADLEIGH

Mark Wadleigh was born with a heart defect, but led a normal life, despite this condition. He began working at a young age and eventually put himself through vocational school for mechanics. In his early 20s, Mark began to work at a local water treatment plant in Glens Falls, N.Y, where he had grown up. The work tasks, which included tasks like disassembling pumps and welding large components together, was physically taxing.

Mark liked his job. By the age of 45, he had worked at the water treatment plant for 23 years. Then, in September 2003, Mike said he felt “excruciating pain, like my nerves were going from zero to 1,000 miles per hour.”

Frightened, Mark went to the hospital, where he was told that he was having a heart attack. The local hospital did not have the equipment to treat him, so an ambulance raced him to another hospital where he had 10 hours of open-heart surgery. During the surgery, Mark’s aortal valve was found to be blocked; it was replaced with a titanium valve. The surgeon had to cut through Mark’s sternum. In the course of doing this, one of his lungs was inadvertently punctured. Recovery was difficult. After the surgery, Mark was prescribed four medications, in addition to the medications that he already took for anxiety.

Mark’s doctors told him he could not leave the hospital until he could walk a certain distance, so he practiced walking every day. On the fifth day, he walked the required distance and was discharged, excited to return to his normal life.

Mark’s goal was to return to work. But his chest still hurt where his sternum had been cut and he was often short of breath. His cardiologist told him he could not return to work—his heart was permanently damaged. Mark contacted his employer and asked whether there was work he could do, given his limitations, but was told there was nothing. He lost his job, his employer-based health insurance, which had covered most of his hospital costs, and his short-term disability insurance. When his cardiologist recommended he apply for SSDI in the winter of 2004, Mark saw no other choice. He was initially rejected, but Social Security subsequently approved him for benefits.

While Mark waited for his SSDI payments to begin, he could not afford to continue to pay for health insurance through COBRA. He called every health insurer in the state, but due to his pre-existing condition, private insurance was not affordable. He started borrowing money from his brother and mother to pay his bills. Mark had worked from an early age and valued his independence. Borrowing money from his family was against the values he had held throughout his life.

For a brief time Mark qualified for Medicaid through a spend-down, but when he began to get SSDI checks of \$1,100 per month in the spring, his income made him

ineligible for Medicaid. Mark also earned too much to qualify for other state or county programs, and he felt helpless. “I always had a job, I didn’t know what to do,” he said. His only choice was to be uninsured.

When Mark finally began receiving SSDI, it was retroactive to when he should have first been approved. He used this income to pay his mother and brother back, though they insisted he did not have to do this.

Mark could not afford to pay for visits to his cardiologist, primary care physician, or psychiatrist. He continued his psychiatric treatment only because his psychiatrist agreed to write off the cost. Despite the expense, Mark also continued to see his cardiologist and primary care physician every month to have his blood checked. Some costs were written off to charity; others Mark could not pay.

He also could not afford his prescriptions. Feeling desperate, he swallowed his pride and asked his cardiologist for samples, which were freely given. But Mark was too ashamed to also ask for two inhalers. Near the end of the waiting period, when he felt he could not survive without the inhalers, Mark once again asked his doctor for free samples

Even though he had only just finished paying back his mother and brother, Mark now had to ask them for more money for anxiety medications. He tried to go without as much as possible, but the stress over his health and finances made it impossible.

While Mark was in the waiting period, he received \$1,800 in hospital bills. His case was eventually sent to a collection agency. In addition, credit card companies began to demand he pay his bills. In some situations, Mark was able to work out payment plans. In desperation, he told one agent his income and asked, “Can you live on this much money a month?” The agent said, “No.” “Well, I can’t either,” Mark replied. Another collection agent advised Mark to sell everything he owned. He would have lost everything if it had not been for financial assistance from family.

Mark got Medicare in March 2006. For the first time in years, he could pay his doctors and not rely on charity for his prescription drugs. One of the most helpful benefits is that Medicare covers the medications he takes for anxiety. Getting Medicare was, he said, “a big relief.”

Mark has since paid off three of his credit cards and, after working out a payment plan, the hospital bills. Mark still has nearly \$2,000 in debt but is confident he will soon be able to pay this off. Today, Mark spends much of his time helping his mother provide child care for several children in the neighborhood, including his niece and nephew.

ROXIANNA MCCUTCHAN

Roxianna McCutchan was born with a rare muscle disease called arthrogryposis multiple congenita. Her doctors predicted that she would not live to be 13 years old, but she is now 36. Roxianna's childhood was anything but normal. The disease caused her arms to bend permanently at her elbows, made it hard to bend her knees and hips, and resulted in one leg being four inches shorter than the other. Simple actions like walking and sitting were painful and sometimes impossible. Despite a metal rod placed in her spine when she was 10, her spine became so twisted that it prevented her chest cavity from growing to a normal size. This forced her to make do with an 80 percent reduction in lung capacity and pulmonary hypertension, a constriction of certain arteries that places great stress on the heart and further inhibits blood flow to the lungs.

In spite of her health problems, Roxianna celebrated her 13th birthday and many more, eventually becoming a clerk and dispatcher for the Rockport Police Department in Victoria, Texas. But, over the years, Roxianna's underdeveloped muscles and compressed lungs began to make simple office tasks, like speaking on the phone, difficult. She required oxygen around the clock and suffered from a cough that was not strong enough to dispel fluid from her lungs, predisposing her to infection and transforming common colds into serious illnesses like pneumonia. Wanting to work, she resisted applying for disability benefits. But in 2002, when she was 33 years old, she felt she had no choice but to take her doctor's advice and apply for SSDI. She became eligible for benefits the same year, only having to wait the mandatory five months before receiving her first check.

When the first SSDI check arrived, Roxianna was surprised to learn she was still ineligible for health insurance. With a life history of health problems that discouraged insurers and a \$796 per month SSDI check insufficient to pay for COBRA, Roxianna found she had no health insurance when she most needed it. She was only able to visit her primary care physician because he agreed not to charge her and was unable to receive treatments from specialists or to fill prescriptions. Roxianna found herself unable to treat illnesses like common colds, which, combined with her other health problems and low immunity, often developed into more serious illnesses. In 2003, Roxianna found herself in the hospital four times for conditions that could have been treated with basic care. She could not even afford to buy the oxygen she constantly required, having to depend instead on the charity of her church to purchase it for her. Roxianna suffered from the loss of self-respect and the stress of depending upon others. Her recurring anxiety caused her to suffer frequent panic attacks as she waited for Medicare coverage to begin.

In January 2005, Roxianna finally became eligible for Medicare. By then she weighed 73 pounds and was \$20,000 in debt: it was time to rebuild her life. “I am now able to get the things I need to make my life easier and less painful. If it hadn’t been for the kindness of others, I don’t think I would have survived,” she said. Thanks to Medicare, Roxianna has been able to visit specialists who can best treat her various conditions. She has been able to order devices, like wedged shoes, that alleviate her discomfort and allow her to lead a more active life. Instead of landing in the hospital if she catches a cold or flu, she can now be treated without the fear of unwieldy medical bills. Medicare and the Qualified Medicare Beneficiary Program pay the entire cost of the oxygen she requires.⁸ She no longer suffers from panic attacks.

Roxianna has begun to repay her \$20,000 debt and is no longer forced to rely on charity. Medicare has helped her most by reducing her anxieties and rebuilding her self-esteem. “The stress level decreased dramatically when Medicare started. I got some of my self-respect back. I am now able to get the things I need to make my life easier and less painful,” she said.

ALICE KIEFT

For nearly 18 years, Alice Kieft lived in Haverhill, Mass., and worked as a manager at a global travel company. In the autumn of 2002, when she was 51, Alice broke her foot falling down a friend's staircase. The fracture was not initially identified on the X-ray by her doctor, who told her she had a sprain and should stay off her foot for two weeks before returning to work. Alice took this advice but when she got back to work her foot hurt if she put any weight on it. She rented a wheelchair and saw an orthopedist who discovered she had a serious fracture that had gotten worse without treatment. The orthopedist put her ankle in a cast that stretched to her knee and told her not to leave bed for two months.

Prior to this injury, Alice had been struggling with diabetes, depression, severe arthritis, and fibromyalgia, a disease characterized by muscle pain and fatigue. The arthritis and fibromyalgia worsened during Alice's two months of prescribed bed rest. Her muscles stiffened, requiring a prescription for additional medication to combat the pain. During this same period, Alice stopped responding to her depression medication.

At first, Alice's situation seemed manageable. The company where she worked, in addition to allowing her to keep her health insurance coverage, continued to pay her full salary during her first month of leave, and then 70 percent until January 2003. Alice believed she would return to work. In fact, she was depending on it because she had little savings, never thinking she would retire early.

By the spring of 2003, Alice found it almost impossible to walk up or down stairs or sit comfortably long enough to watch a movie. Alice said her arthritis became "overwhelmingly painful" and her depression got worse. "I was a mess," she said. She no longer received a salary from her former employer and could not afford the copayments for her frequent visits to specialists and her five medications. She began to charge these costs to different credit cards.

Very quickly, Alice was forced to recognize her mounting debts and acknowledge that she would not be able to return to work. By the time she decided to apply for SSDI, she was too debilitated to go to the Social Security office in person and had to apply via mail with the help of a lawyer. Alice won her SSDI case, but had to wait until September 2003 to receive her check. While waiting for benefits, she had no source of income.

Alice used her first SSDI check to make the minimum payments on her credit cards and pay her mortgage and utilities. She tried to apply for food stamps and other low-

income benefits, but was rejected because her SSDI check set her just above the income limit. Desperate to save money, she relied on her mother and brother to pay her mortgage and utilities and turned to food banks. Most of the food that was offered to her was not appropriate for diabetics, causing her health to decline further. She still finds it difficult to remember this harsh period of her life.

“If it had not been for my mother and brother, I would have been homeless. I felt like a failure. I felt like it was the end of the world and going to the food bank was the final straw. I was raised so that you don’t take charity and you don’t take welfare,” she said.

Constant muscle pain made Alice too scared to stop seeing her doctors or to stop taking all of her medications. The pain, combined with stress and depression, caused a spike in weight, further exacerbating her diabetes and requiring an increase in medication. In addition to these problems, in the fall of 2003 she was diagnosed with narrow angle glaucoma, a rare eye disease that required surgery and more medical care. By this time, Alice had run up \$28,000 in credit card debt. She felt her only option was to declare bankruptcy.

Alice’s declaration of bankruptcy required her to pay \$160 per month to her creditors for the next three years; she would be legally out of debt by September 2006. Despite the elimination of most of her debt, Alice’s day-to-day situation was worsened by her bankruptcy. She could not afford to pay the \$160 per month on top of her basic necessities and medical costs. She sold her condominium and planned to move to Kewanee, Ill., where the cost of living was lower and she could be near her family. “Emotionally, I was devastated,” she said

Midway through her trip, Alice had car problems and then developed a bronchial infection that forced her to seek out a health care center. Unlike Medicare, which generally allows access to doctors virtually anywhere in the nation, Alice’s employee health coverage—which had continued through the unpaid medical leave her previous employer gave her—did not cover any medical services in this area. She had to pay the entire cost of her medical care. Less than one week later, Alice arrived in Illinois roughly \$11,000 poorer. The unexpected health care costs, coupled with the costs of setting up a new home, consumed the rest of her funds from the sale of her home.

In October 2004, Alice’s employee health insurance ran out and she had to pay \$500 per month to continue coverage through COBRA. Terrified to increase her debt, she had no choice but to withdraw \$5,000 from her 401K retirement fund. The \$5,000 was counted as income by the state of Illinois, again placing Alice above the income limits

for government programs that could help her. She was able to get most of her prescriptions for free or at minimal cost through patient assistance programs. She used retirement funds to cover COBRA payments, copayments, and other medical costs until the following April, when she finally became eligible for Medicare. “Medicare helped tremendously,” Alice said.

Alice signed up for a Medicare preferred provider organization and felt the transition was smooth. The monthly copayments she paid to see her doctors totaled less than \$100, much less than they had been under COBRA. For the first time, she could actually afford her health care.

Alice is still not healthy, and there are days when she can barely move because of pain. In addition to physical pain, Alice began having panic attacks shortly after she relocated to Illinois. Her psychologist thinks that the attacks, which make it momentarily impossible to breathe, are a result of the stress she suffered during the last two years.

Despite ongoing problems, Alice links her qualification for Medicare to the time when she began to put her life back together. “I [began] to feel like I was a real person and I was going to make it,” she said.

Alice’s reclamation of her life involved socializing and volunteering at the local Humane Society. She now serves on the Humane Society’s board and acts as treasurer. In September 2006, Alice made the final payment on her debts. Next she hopes to pay back her mother and brother, and is thinking about starting an eBay business. In addition, the experience of waiting for Medicare has given her a desire to help other people in her position. To this end, she has become involved in health care advocacy work. If Alice had been able to transition to Medicare at the same time she became eligible for SSDI, she could have avoided bankruptcy and much of the subsequent trauma she suffered.

JEFFREY GARRETT

Jeffrey Garrett was in his mid-50s, living in North Manchester, Md., and working in Washington, D.C., as a fund-raiser for a nonprofit organization, when he was diagnosed with multiple myeloma, a type of blood cancer, in December 2004. Jeffrey was too sick to continue working; he left his job and applied for SSDI.

After being diagnosed with cancer, Jeffrey wanted to return to the town in Indiana where he had lived and where he still had close friends. In Indiana, Jeffrey had also worked in the nonprofit sector. He was a fund-raiser for organizations; provided development, management, and other services to nonprofit organizations through his consulting firm; and served as a training facilitator for the Indiana Nonprofit Resource Network. Before moving east, Jeffrey had been appointed executive director of the North Manchester Chamber of Commerce.

When Jeffrey's friends learned he was sick and wanted to return to Indiana, they immediately set about raising funds through their church to help with living expenses. To pay for health care, Jeffrey planned to apply for Medicaid in Indiana. He was worried whether he would qualify for Medicaid in Indiana, but decided to take the risk and move.

In April 2005, Jeffrey's friends headed to Maryland to bring Jeffrey and his belongings back to Indiana. Thanks to their fund-raising efforts, he could afford rent on a subsidized apartment and basic household expenses.

Jeffrey applied for Medicaid in Indiana and was immediately approved. He was distressed to learn, however, that Social Security denied him SSDI benefits. Jeffrey turned to a lawyer to help him appeal his case.

Meanwhile, Jeffrey's doctor recommended a bone marrow transplant to treat his multiple myeloma. He was hopeful this would extend his life. He had the transplant at a hospital in Fort Wayne and Medicaid covered it. Soon after, in September, Jeffrey received good news: his SSDI was approved, retroactive to May 2005. He was thrilled.

But good news quickly turned to panic. Getting SSDI benefits meant he would have to spend down to continue his Medicaid coverage. Neither he nor his friends could find a way for him to make ends meet on \$600 a month, which was all that would be left of his SSDI check after the \$1,000-per-month spend-down. His friends feared they could not raise more money to support Jeffrey and he would be uninsured until his Medicare coverage began in May 2007.

“It was a real Catch-22,” said Jeffrey’s friend.

Jeffrey died in October 2005 at age 56, after a courageous battle with cancer, and without ever reaching eligibility for Medicare.

When Jeffrey first learned that the Medicare Rights Center was interviewing people for its 24-month Medicare waiting period project, he contacted the office and asked to participate. Jeffrey explained that he had spent most of his life working to help others but was now too sick to work. He said he wanted to share his personal experience of waiting for Medicare if it could help put an end to the Medicare waiting period policy.

The initial interview was the only contact MRC had with Jeffrey.

DEBORAH TURNAGE

Deborah Turnage lived in Waco, Texas, where she had moved to be near her oldest daughter's family. In the early 1990s, Deborah was diagnosed with lupus and fibromyalgia, both of which cause muscle pain and fatigue. During the next decade Deborah developed additional health problems, including asthma, sleep apnea, anxiety, and back pain caused by the compression of nerves in her lower spine.

Despite her poor health, Deborah continued to work in quality control for an advertising company. In 2003, at the age of 49, she had a stroke. While she recovered, her company relocated and she lost her job. She could not afford the COBRA payments to maintain her insurance and lost her health care coverage.

Deborah's health problems required her to be evaluated by specialists frequently. She was prescribed 14 medications for her different conditions. Without health insurance, the prescription drugs were too costly for her to afford. To regain health coverage, Deborah found another job—but was laid off three months later, owing to, as she calls it, the “brain fog” associated with lupus. Unfortunately, lupus has central nervous system manifestations and Deborah found she could not concentrate at work. At the time she was laid off, her new health insurance coverage had not even begun.

Deborah's health problems became worse, primarily because she could not afford to see the many specialists managing her conditions, including a rheumatologist for severe arthritis and lupus, a neurologist for the brain effects of lupus and nerve damage, and a pain management specialist who had prescribed braces, physical therapy, and injections. Nor could she afford to see the ophthalmologist who monitored her eyes frequently. Medications that treat lupus can cause retinal damage and even lead to blindness if not monitored closely.

After being laid off, Deborah's only option was to apply for SSDI. Initially rejected, she appealed and quickly won her case, waiting just five more months before checks of \$1,000 per month began arriving. During this time, Deborah spent the last of her savings and was forced to turn off her telephone, discontinue cable and Internet services, and conserve electricity just to pay the rent.

In January 2005, Deborah was still uninsured. Fortunately, she found a small county health insurance program that paid 60 percent of the cost to see one of its in-network primary care physicians and 60 percent of the cost of prescriptions. Even with this help, Deborah could not balance her high medical costs and necessities like food. In addition, her monthly SSDI check put her income above the limit for other assistance

programs. Deborah used half of each SSDI check to pay rent and the remainder for all other expenses. She tried to earn extra money by doing sewing jobs but could not find many customers. Quickly, treats like take-out food and movies became distant memories. Deborah recalled that she, “[couldn’t] even buy Christmas presents for my grandkids.”

Even though the county health insurance lowered the cost of Deborah’s 14 prescriptions, they were still too expensive and she had to balance medical costs with daily needs: “If it’s a month when I have to go to the doctor, I feel like I have to rob Peter to pay Paul,” she said.

Deborah often took her prescriptions every other day or less frequently to make them last longer. If a prescription ran out before she could refill it, she simply did without it. Several times Deborah had to ask her daughter for money. “I feel like I’m losing my independence,” she said.

Meanwhile, Deborah’s medical treatments were inadequate. Her primary care physician did not have specific knowledge of her conditions. When Deborah’s breathing problems increased so much that she could not talk on the phone for longer than a few minutes, the doctor prescribed medicine that Deborah took using her daughter’s old nebulizer. Throughout the 24-month waiting period, Deborah constantly worried about not being able to see specialists.

During Deborah’s second year in the waiting period, she had such severe headaches that her primary care physician told her to get an MRI, which showed white spots in her brain that doctor attributed to the spread of lupus. Deborah could not afford to see a neurologist and worried her brain would be permanently damaged.

County health insurance did not cover the nearly \$1,400 cost of the MRI, which, along with other X-rays and tests (including a \$4,000 stress test and \$1,600 in cardiology work), added dramatically to Deborah’s growing debt. Furthermore, despite getting care, Deborah’s health did not improve. Regarding her debts, she said, “I [do] the best I can and send them \$5 and \$10 every month.”

Throughout the waiting period Deborah’s joint and muscle pain became more acute. Her primary care physician attributed the pain to lupus and prescribed expensive prescription pain killers. Deborah tried to decrease her costs by taking ibuprofen, but as time passed this became less effective. In her last months in the waiting period, her body ached so much that often she could not stand up straight or walk. Her sleep apnea grew worse, but she could not afford the treatment her doctor recommended. Near the end of

the waiting period, Deborah noticed her vision had become blurry, but she could not afford to see an ophthalmologist. “I am just waiting for Medicare,” she said.

Because of mounting debt and health problems, Deborah began experiencing anxiety. Through the county health insurance, she saw a mental health therapist who helped her cope with her anxieties. The therapist also helped her find a dentist who did not charge her to treat a serious toothache. It was hard for Deborah, who had always seen herself as hardworking and self-sufficient, to take advantage of free services like these, which she described as “intended for homeless people.” She also commented that “[while] there are many resources out there, I really had to struggle to get them.”

The summer before Deborah began receiving Medicare she started experiencing “unbearable electrical shocks” between her calf and toes and general numbness in her extremities. This, added to her other health problems, terrified her. Her therapist found a neurologist who agreed not to charge for services. He diagnosed her with neurosarcoidosis and peripheral neuropathy—damage to the tissues in her central nervous system and nerves. He explained that the white spots revealed by the MRI were the result of a series of ministrokes. The neurologist prescribed medicine to control Deborah’s pain, but said the damage done could not be repaired.

When Deborah finally became eligible for Medicare in September 2006, she had close to \$20,000 in outstanding medical bills. She learned from the Medicare Rights Center that she qualified for a program to pay her Medicare Part B premium. She was also approved for Extra Help, a federal benefit that significantly reduces her drug costs.

Deborah saw an ophthalmologist. In the course of prescribing glasses, he found she had developed cataracts, which were responsible for her blurry vision. Another doctor diagnosed her with diabetes. Medicare now covers a glucose monitor that she uses to control the disease. Through Medicare, Deborah has gotten a power wheelchair that she uses when extreme pain prevents her from walking. She is grateful to the Medicare program for allowing her to visit specialists—including her mental health therapist—who can accurately diagnose and effectively treat her health problems.

Deborah’s health seriously deteriorated while she was waiting for Medicare. She developed a brain inflammation that might have been avoided if her medications had been properly monitored by specialists. It is possible that many of her current health problems—including the pain and cumulative disabilities that require her to have a wheelchair—could have been averted if her health had been monitored closely. Her disease progressed while she did not have adequate health insurance.

BOB JONES

In 2001, Bob Jones graduated from law school in Michigan and moved to Louisiana, where he began working at the Equal Employment Opportunity Commission. He investigated accusations of discrimination in the workplace, enjoying the work so much that he put off taking the bar exam. Bob was in his mid-30s when his career and life were interrupted by a serious accident. In June 2003, he was planting flowers on his apartment's balcony when he rested his weight on the railing and fell 18 feet to the cement pavement below. The impact of the fall was severe enough to crack the sidewalk, smash his right foot, and injure one of his vertebrae.

Bob was rushed to the hospital where a surgeon inserted roughly 18 pieces of metal into his foot to hold it together, a procedure covered by the insurance Bob had through his job. Doctors told Bob that the vertebra would heal during the next few months and to stay in bed during this time.

Unable to take that much sick time, Bob was forced to leave his job. He had not expected to stop working and did not have significant savings. Without any source of income, he applied for SSDI. He initially paid for COBRA through his partner's employer-based COBRA coverage, which was less expensive and more comprehensive than his own plan. Even so, the monthly premium was high.

By the spring of 2004, Bob still could not walk and the intense pain in his foot and back was worsening. At this juncture, his partner's insurance company terminated Bob's COBRA coverage because the couple was not married. Without health insurance, Bob had to pay \$800 to get a CAT scan of his foot. The scan revealed that most of the bone in his foot was "like dust," he said, and the metal would have to be removed. Bob needed more surgery.

Bob knew how expensive it would be to have surgery without health insurance. He was also aware that people with disabilities could get Medicare, and so he called Social Security to ask about his disability application, the precursor to Medicare. "All I wanted was surgery on my crushed foot so I could walk again," he said.

It was not until the fall of 2004, after months of struggling with the determination process, that Bob was finally found to be eligible for the benefit. Social Security recognized that Bob should have been approved for SSDI much earlier, so he was awarded benefits retroactively and received payments back to the fall of 2003. He would

become eligible for Medicare two years after the date he should have first begun to receive SSDI benefits—in December 2005.

It was only after being approved for SSDI that Bob learned he would not become eligible for Medicare immediately.

“I said that I needed Medicare through the entire process, and no one ever mentioned the waiting period. I did all that work to get disability [benefits] when I needed surgery and was in extreme pain; I thought that would qualify me for Medicare,” he said.

The pain in Bob’s foot and back steadily increased and he had very little money saved. He had qualified for food stamps, but once he began to get his SSDI check for \$1,114 per month—an amount based on his average earnings while he worked—he became ineligible. SSDI payments, in fact, prevented him from qualifying for any low-income programs.

Desperate for insurance, Bob found a provision in the law that said if “irreparable injury” would be caused if a person was not treated, then that person must be given Medicaid. A judge felt Bob’s situation fit this description, ruling he could get Medicaid with a \$3,000 spend-down. This meant that he would receive health benefits through Medicaid for a three-month period after he spent \$3,000 out-of-pocket.

Bob discovered his surgeon and anesthesiologist, who had all his medical records, did not accept Medicaid. In pain, and viewing surgery as the only option, Bob used the money he had been awarded from his accident to pay his surgeon \$7,000 and his anesthesiologist \$2,000 for the foot operation. Bob’s foot pain had become so severe that he was prescribed a morphine pump to use when he returned home to combat pain. Following release from the hospital, Bob used funds left over from the cost of the operation and the pump to meet the \$3,000 Medicaid spend-down, in case he needed emergency care.

The goal of the foot surgery had been to remove the metal in Bob’s foot and fuse the bones together, but the operation failed. Now Bob could not walk or afford more surgery or treatment from the doctors who did not take Medicaid.

“The final bill drained my back-pay almost to a penny,” Bob said.

Then Hurricane Katrina hit Louisiana and Bob, forced to evacuate like so many people, moved to Indiana. All of his medical records, including MRIs and CAT scans, were lost, along with his wheelchair, walker, and an electric cooling machine used to decrease painful swelling in his foot.

In December, Bob became eligible for Medicare and had no trouble finding a doctor and orthopedic surgeon in Indiana who accepted it. Medically necessary MRIs, covered by Medicare, revealed that Bob had actually fractured four of the vertebrae in his back, which had remained untreated for more than two years. During this waiting period, blood had leaked into Bob's spine, requiring two operations, which repaired much of the spinal damage. Medicare also enabled Bob to receive physical therapy for his foot and back, which he continues today. In April Medicare paid for Bob to get a spinal cord stimulator. This, coupled with his other treatments, has significantly reduced his pain to such an extent that he no longer needs a morphine pump.

“Medicare is the only reason that I can receive any treatment,” he said. “This is all because I have Medicare. I was and am dumbfounded that I could be approved as disabled, but not receive Medicare.”

Bob's surgeon has told him that he will need more surgery because his condition remained untreated for so long that his bones became “hardened” in place. Fortunately, Medicare will cover the operation. Bob hopes that one day soon he will be healthy enough to take the bar exam in Indiana and return to work.

NOTES

¹ P. F. Short, D. G. Shea, and M. P. Powell, [*Health Insurance on the Way to Medicare: Is Special Government Assistance Warranted?*](#) (New York: The Pennsylvania State University and The Commonwealth Fund, July 2001).

² G. F. Riley, *Health Insurance and Access to Care Among Social Security Disability Insurance Beneficiaries During the Medicare Waiting Period* (Washington, D.C.: Centers for Medicare and Medicaid Services, Fall 2006).

³ B. Williams, A. Dulio, H. Claypool et al., [*Waiting for Medicare: Experience of Uninsured People with Disabilities in the Two-Year Waiting Period for Medicare*](#) (New York: The Commonwealth Fund, Oct. 2004).

⁴ COBRA is a federal law that allows certain employees, their spouses, and dependents to keep group health-plan coverage for between 18 and 36 months after they leave their job, as long as they pay the full cost of the premium. Congress passed COBRA in 1986.

⁵ Some pharmaceutical companies offer free or low-cost drugs to people with low incomes through Patient Assistance Programs.

⁶ Medicaid is a state-run program that is state- and federally funded and covers medical expenses for people with very low incomes.

⁷ Hospice is comprehensive care for people who are terminally ill that includes pain management, counseling, respite care, prescription drugs, inpatient and outpatient services, and services for the terminally ill person's family.

⁸ The Qualified Medicare Beneficiary Program is a federal program administered by each state's Medicaid program to help low-income Medicare beneficiaries pay their coinsurance, deductibles, and premiums.

RELATED PUBLICATIONS

Publications listed below can be found on The Commonwealth Fund's Web site at www.cmwf.org.

[*Enhancing Value in Medicare: Demonstrations and Other Initiatives to Improve the Program*](#) (January 2007). Stuart Guterman and Michelle P. Serber.

[*The Cost of Privatization: Extra Payments to Medicare Advantage Plans—Updated and Revised*](#) (November 2006). Brian Biles, Lauren Hersch Nicholas, Barbara S. Cooper, Emily Adrion, and Stuart Guterman.

[*Medicare Physician Payment: Are We Getting What We Pay For? Are We Paying for What We Want?*](#) (July 25, 2006). Stuart Guterman. Invited testimony before the U.S. House of Representatives, Energy and Commerce Committee, Subcommittee on Health.

[*Medicare Extra: A Comprehensive Benefit Option for Medicare Beneficiaries*](#) (October 4, 2005). Karen Davis, Marilyn Moon, Barbara S. Cooper, and Cathy Schoen. *Health Affairs* Web Exclusive (*In the Literature* summary).

[*Medicare at Forty*](#) (Winter 2005/2006). Karen Davis and Sara R. Collins. *Health Care Financing Review*, vol. 27, no. 2 (*In the Literature* summary).

[*Quality of Health Care for Medicare Beneficiaries: A Chartbook*](#) (May 2005). Sheila Leatherman and Douglas McCarthy.

[*Waiting for Medicare: Experience of Uninsured People with Disabilities in the Two-Year Waiting Period for Medicare*](#) (October 2004). Bob Williams, Adrienne Dulio, Henry Claypool, Michael J. Perry, and Barbara S. Cooper.

[*Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs*](#) (July 2003). Stacy Berg Dale and James M. Verdier.

[*Health Insurance on the Way to Medicare: Is Special Government Assistance Warranted?*](#) (July 2001). Pamela Farley Short, Dennis G. Shea, and M. Paige Powell.