



In Their Own Words...

Real Stories from the Patients and Families Suffering from the Medicare Home Infusion Coverage Gap



National Home Infusion Association

Alice Marie Ary

Red Oak, OK

Family is Everything

This past October, Alice Marie Ary noticed she was feeling tired all the time. She had no energy. At 67 years of age, she told herself she was getting older and that the 5k walk she had recently done had taken its toll. She was also losing some weight but did not give it much thought. Her daughters Donna and Brenda felt differently, and convinced her to make a doctor's appointment to have herself checked out. In December, Alice's doctor diagnosed her as having gallstones and told her that the best course of action was to have her gallbladder removed.

In January of this year, Alice underwent the surgery recommended by her physician. The surgery went well so Alice was surprised to learn during a follow-up visit with her doctor that an infection had developed near the surgical incision site. She was given some oral antibiotics and told to keep the wound packed in. She was also directed to Oklahoma University Medical Center to have the stent removed that had allowed bile and small gallstones to drain. Doctors at the facility ran a CT scan of her abdomen which found a large mass of infection that had developed since the surgery. Right then and there Alice was admitted and hospitalized for one week where she was treated with a round of intravenous antibiotics.

Prior to discharge from the hospital, Alice was informed she would require five additional weeks of antibiotics delivered via in-home infusion treatments. However, Alice was discouraged by the news that Medicare would not cover home infusion therapy and explained to the attending case manager that she, "did not have the money to pay for treatment." Alice's daughters inquired about alternatives. They learned that Medicare would cover 100% of Alice's medications, supplies, nursing, and stay if she remained in the hospital or transferred to a skilled nursing facility. This baffled Alice and her daughters, as the price tag for treatment at the nursing facility far exceeded the cost of at-home infusions. "I could not understand why Medicare would cover treatment at the hospital or nursing facility knowing that it could potentially put me at risk of acquiring another infection, but not consider paying for home infusion therapy which represented a fraction of the cost," says Alice.

After much consideration and sacrificing, Alice's daughters agreed to pay the cost of their mother's treatment by charging the bill to their credit cards. Alice was able to undergo her treatments in the comfort of her own home. She was able to watch her grandchildren, visit with friends, and go to church--things she could never have done had she been forced to undergo treatment at a nursing home facility. Today her appetite's back and she is on the way toward gaining the considerable weight she lost in the past few months.

Alice is grateful to her daughters for the help they provided in paying for her treatment but feels stressed over the fact that they sacrificed their own well-being to assist her. "I relied on Medicare to be there for me the one time I needed assistance and it wasn't. I believe I am well today because I had the opportunity to undergo my treatments in the safety and comfort of my own home. I can't imagine the experience I would have had if I had no option but to be stuck in a nursing for five straight weeks!" "Medicare needs to modify its coverage to include home infusion therapy. I am unsure how anyone could be opposed to changing a law that just doesn't make sense. Not only will it contribute toward lowering the cost of healthcare in our country, but it will allow patients to recover in a way that is healthier and safer for them."



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John C. Bradley, Jr.

Wyomissing, PA

Staying on Top of the Game

John Bradley is the senior partner at the law firm of Masano Bradley where he specializes in corporate real estate, probate and school law. He is passionate about his work and has no plans to stop anytime soon. Despite the long hours, he gets satisfaction knowing that he has served his clients to the best of his ability. Throughout his career, John has managed to effectively balance work and family life and maintain a healthy lifestyle. So, when he awoke one morning with his left arm swollen, he was not overly concerned.

Nevertheless, he went to the doctor to have it checked out. The doctor drained the arm and seemingly all was well, but a month later John was back with a swollen arm. The doctor drained the arm again, but this time, took a blood sample and conducted additional tests which indicated John had acquired a staph infection that originated at the elbow. His doctor prescribed a week-long round of antibiotics to be delivered intravenously every eight hours. John and his wife of forty-two years, Barbara, were informed of their options. They were told that Medicare would cover his infusion treatments at an outpatient center or a nursing home but that home infusion therapy was not covered under Medicare.

"In my mind, there was no option," says John. "I may be 65 and on Medicare, but I have a demanding job and clients that depend on me. I can't afford to be out of the office," says John. "I believe in providing my clients with the best possible service. They deserve nothing less. So, if I am unable to meet with them or effectively work on a case, I am doing them a great disservice," John says. "Spending 24/7 in a nursing home for a week was definitely not in my best interests, let alone my clients or my family." "It was not an option my wife and I were willing to consider, even if I was retired. I can't imagine anyone preferring to be stuck in a nursing home when treatment at home is safer and better for one's overall mental health." John was fitted with a PICC line that allowed him to receive his treatments throughout the day while at home and when he was at work.

Later that month, John underwent surgery to remove the infected tissue. Following the surgery, he was placed back on intravenous therapy for another three weeks which he continued to do at home with the help of Barbara. "I was fortunate that I could pay out of pocket for home infusion therapy. I continued to work, spend time with my wife and family. I went out to dinner, exercised, performed chores—all things I could not have done from the confines of a nursing home. Everyone should have the same opportunity. No one should be forced to put their life on hold." It seems ridiculous that Medicare is willing to overpay for treatment in an institutional setting, yet is unwilling to cover home infusion therapy, which represents a fraction of the cost. If our government is truly committed to lowering the cost of healthcare, they need to fix this glitch in the system right now.

"I'm going to keep working and remain active in my community until the day I can't get up," John says. Interestingly, a 2013 U.S. Census Bureau report states that "the percentage of people 65 and older in the labor force increased from 12.1 percent in 1990 to 16.1 percent in 2010" and that the 65 and older population will increase by over 67 percent between

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2015 and 2040. "If we are to believe this, Medicare needs to meet the changing needs of its beneficiaries. Unless a person requires hospitalization for a serious illness, there is no reason why medications cannot be infused at home. For Medicare to turn a blind eye and refuse to look at the realities of today's changing world, and ignore the safety and cost-savings aspects of home infusion therapy is beyond comprehension."



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Judy K. Colburn

Glenvil, Nebraska

A Mother's Gratitude for her Daughter

Sixty-seven year-old Judy Colburn remembers looking at her swollen finger one morning and thinking that what she thought looked like a spider bite was definitely now infected. Not wanting to take any chances, she went to her doctor who gave her antibiotics via injection. A follow-up visit the next day resulted in her doctor recommending that she see an infectious disease specialist. While the specialist suspected Methicillin Resistant Staphylococcus Aureus (MRSA), he preferred to have Judy tested at the hospital to confirm his diagnosis. As it turned out, Judy's skin infection was indeed caused by MRSA. The infected area usually starts out as a small bump resembling a pimple or spider bite, and increasingly worsens.

Judy was prescribed a course of Vancomycin, a strong antibiotic administered intravenously, twice a day for two weeks. Upon hearing the news, she automatically assumed that she would receive her treatments at home since she wasn't sick. However, the very next minute the doctor explained to her that she would need to receive her treatments at the hospital on an outpatient basis as Medicare would not cover the cost of home infusion. "At first I did not understand why I had to go through the expense and inconvenience of going to the hospital twice a day. I was very upset. I do not drive and the cost of a cab to take me back and forth to a hospital that is 15 miles away was not an option I could afford," says Judy. "I knew that the treatments at home would be less expensive than receiving them at the hospital, but as a retiree on a limited income, I could not pay for home infusion therapy out of pocket."

As with other Medicare patients, the cost of Judy's antibiotics would be covered, but the supplies and equipment needed to receive infusion treatments at home would not. "My daughter Patty and I spoke exhaustively about the situation and decided that she would drive me to and from the treatments. I felt terrible, but there was nothing I could do."

While difficult, Judy's daughter took time off from work at no pay to take her mother to the hospital twice a day. Traveling 60 miles a day presented an additional financial burden. "Patty would take me once at 7:45 in the morning and a second time at 9:00 at night. Each time, she waited the hour and a half the infusion lasted," says Judy. "In between that, she drove her son to work. She was exhausted. The sacrifice my daughter has had to make is more than I could expect of anyone. She has given so much of herself".

"I cannot understand how Medicare is willing to cover the cost of a more expensive course of treatment at the hospital, but is unwilling to pay the cost of infusion at home which is less costly and safer for someone like me battling infection. It just doesn't make sense," Judy states. "My daughter means the world to me. I am so grateful for all she has done for me, but putting such unnecessary burden on your loved ones, is one reason legislation to modify the current Medicare laws is needed."



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Larry Cook

Omaha, Nebraska

A Caregiver's Heart

Larry Cook gets up early every morning to take his six-year old grandson Connor to school. He does it to help out his daughter, but mostly he does it out of love. Caring for his grandson and maintaining a close relationship with his other five grandchildren means the world to him, so it's a routine he enjoys. Life is good.

It was not long ago that Larry would wake just as early to make breakfast for his wife Linda. For the past two years Larry would bathe her; help her get dressed; make her lunch and dinner; and sit with her to keep her company. He rarely left her side. When she was too sick to remain at home, he was at the hospital from early in the morning to late at night. This became his routine. But it's a routine Larry embraced proudly, not only because he felt it was the right thing to do, but because of the great love he had for his wife of fifty-two years. He was her primary caregiver and remained by her side the entire time she was ill with complications of lung cancer.

Larry and Linda's love story goes way back to when they were teens. High school sweethearts, they married a year after high school and for fifty-two years were the best of friends. His job with Union Pacific Railroad gave them the unique opportunity to live in seven different states and together with their two kids, Larry and Linda enjoyed experiencing different towns and traditions. In 1996, at the age of 54, Larry retired, giving them more freedom to travel, see family, and enjoy the everyday events that make life memorable. Unfortunately, life changed in 2003 when Linda was diagnosed with lung cancer. She had surgery to remove her left lung and handled the chemotherapy and radiation treatments that followed rather well. However, a year later she suffered a compression fracture of the back, quite possibly as a result of the treatments she received. Over the course of the next few years, Linda endured three additional compression fractures. While the pain slowed her down, she managed through it to maintain her daily schedule. Slowly, however, her health deteriorated.

In 2008, she contracted pneumonia. While she recovered, she never quite regained her strength and in late 2009, Linda developed pneumonia again. From that time on, throughout the course of the next two years, she was in and out of the hospital and rehab with multiple bouts of pneumonia.

"We were told that Medicare did not cover home infusion therapy," says Larry. "As a retiree, any unforeseen cost had to be taken into consideration when deciding on treatment options, particularly healthcare related expenses," he says. "I did not understand how Medicare was willing to incur the tremendous cost of hospitalization or a skilled nursing facility, but was unwilling to pay for the infusion treatments at home, which did not even come close to the hospital and rehab charges." After considering the additional costs that would be incurred, Larry and Linda made the decision to self-pay. "I did not know how much time she had left, but I knew that I did not want her confined in a hospital or a skilled nursing facility where she could possibly get yet another infection. I wanted her to enjoy the comfort of her own home where I would be able to administer the infusions myself," Larry adds.

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She was fitted with a PICC line, for the fourth time in three years, which enabled her to receive the intravenous antibiotics she needed every eight hours in the comfort of her own home. Being home lifted her spirits. It allowed Linda to be surrounded by her family," Larry adds. "She enjoyed her grandchildren and we wanted them to be able to visit her as often as possible. This was important to her well-being and mine."

Sadly, Linda passed away in her home this past November. Larry lost the love of his life, but he finds solace in the fact that she was able to spend time at home. Larry has no regrets in having to self-pay for the home infusion therapy, but feels strongly that Medicare should cover the cost of infusion at home. "It is wrong for Medicare beneficiaries to be forced into the confinement of a skilled nursing facility or hospital to receive treatment that they can receive at home and at a lesser cost," says Larry. "I have friends who are experiencing a similar situation and it is terribly disconcerting to see them go through what Linda and I did. Why add to the burden of families that are already suffering, especially when the cost of hospitalization significantly outweighs the cost of treatment at home?"

"The devastating battle my wife and I experienced is over, but I remain her voice in trying to create positive change within the Medicare system. Having the treatments at home meant so much to my wife and I; it should be the norm, not the exception. Congress needs to pass new legislation that will ensure Medicare coverage of this vital service. Not only will it benefit patients, but it will contribute to lowering the cost of healthcare in this country."



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Jeanette J. Ernst

Cedar Rapids, Iowa

The Days Ahead

Jeanette's courage has been tested many times. As a nineteen-year colon cancer survivor, she's had to endure the unbearable. One could say a million and one things about the devastating and complicated health challenges she's faced. Yet, for the past twenty years, Jeanette has faced adversity with faith, hope, courage and an iron-clad determination. At 72, she has kept pace with her illness wearing a smile and a positive attitude.

Jeanette's life changed in November of 1992 when she was diagnosed with stage IV colon cancer. Completely unexpected, she thought her weight loss and irritable bowel condition were due to a hectic schedule and stress. Following a colonoscopy, she received the devastating news that she had a large mass in her small intestine. After absorbing the reality of what she had just heard, along with the fear, anxiety, and anger that accompanies such news, Jeanette dealt with her diagnosis the same way she met other challenges in life: head on. "Looking back, I had no idea how much my life would change as a result of this diagnosis. I had no other option but to forge ahead and fight the battle ahead," Jeanette says.

Doctors performed surgery that removed about three feet of her small intestine followed by six weeks of radiation and six months of chemotherapy. She was given a thirty-percent chance of survival. Yet, survive she did. "Hope was my constant companion. But more importantly, I was grateful for the love and care of my husband Jack and the support of my children. It was an incredibly difficult time for our family, yet somehow we were blessed. I survived. I was one of the lucky ones," says Jeanette.

But more was to come. Fifteen years later, in February of 2007, Jeanette developed a rectovaginal fistula (RVF). "The emotional distress and physical discomfort were agonizing," she says. "Unfortunately, my problems did not end with this condition," she adds. A PET and CT scan each revealed considerable scar tissue and damage to her colon, bladder, kidneys and intestines that doctors believed were the long term results of radiation therapy. A long thirteen hour surgery to repair the fistula left an open wound in her abdomen that required continual vigilance and time to heal.

Thanks to the assistance of home health aides, Jeanette was able to recover at home but, she continued to feel ill. She was experiencing nausea and vomiting and was tired all the time. Her doctor ran tests but urged Jeannette and her husband to take a small vacation to mentally recover from all the health issues she had endured. They were gone one day when she received an urgent call from her doctor requesting that she return immediately. Tests showed that her magnesium levels were dangerously low. She ended up in the emergency room and later in intensive care leaving doctors mystified over how she survived with such low levels of magnesium.

Once again she felt as if her world was caving in on her. At the hospital she learned that her body was no longer able to properly absorb magnesium and that to survive, she would need to undergo life-long intravenous treatments of magnesium. Today, Jeanette is infused with magnesium and electrolytes three times a week at three to four hour intervals.

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At first, Jeanette had private insurance and was able to self-infuse in the comfort of her own home with the guidance and support of her local infusion agency. However, once she went on Medicare, home infusion therapy was no longer an option. "Medicare will cover my treatments at a hospital or nursing home, but will not cover the cost of infusion at home, which makes no sense at all," says Jeannette. Medicare Part D will cover the cost of the medicine itself, but not the infusion supplies, equipment or professional services required to undergo infusion therapy at the home.

"I knew that the treatments at home would be less expensive than receiving them at the hospital, but as retirees on a limited income, my husband and I could not pay for home infusion out of pocket. To go from having infusions in the comfort and safety of my own home to the inconvenience of a hospital is difficult enough. I've already experienced one infection. I don't want another! I have been through so much in my life and the fear of getting an infection is frightening." And, always, always on my mind is the thought of getting older. What happens when I can no longer get to the hospital three times a week?

Despite having to deal with a colostomy and the need for infusion the rest of her life, Jeanette considers herself fortunate. She's survived multiple health challenges and is happy she is able to lead a full life with her husband, children and grandchildren. Giving back to the community is important to her and as such she heads an ongoing drive to supply local children in need of clothes and school supplies. "I maintain a positive attitude, but always worry about the days to come. The issue with Medicare must be resolved. For me, it's a simple issue of survival.



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Nancy E. Helms

Yorktown, Virginia

One Step at a Time

Each day, seventy-two year old Nancy Helms is getting one step closer to walking without the aid of her walker. She tires easily, but she is sure to do the exercises that will strengthen her legs and make her more mobile. Nancy is a native of North Carolina but she made Virginia her home when she married her husband Bill over 51 years ago. Sadly, Bill passed away this past June at the age of 74 following complications related to COPD or chronic obstructive pulmonary disease, a serious lung disease where the airways—tubes that carry air in and out of your lungs—are partly blocked, making it hard to get air in and out. COPD is also referred to as emphysema or chronic bronchitis.

Together, Nancy and Bill raised two boys—Hal and Craig, and have three grandchildren, four step-grandchildren and two great-granddaughters. Both educators, Bill was an elementary school principal and Nancy, who has a doctorate in education, was a teacher and guidance counselor. Nancy retired as the director of guidance and testing for the Hampton City Schools but later worked part-time as a professor at Old Dominion University in Norfolk and later as a professor at the College of William and Mary in Williamsburg.

Throughout her lifetime, Nancy's has had her share of health challenges but she has continued to persevere with steadfast determination. A number of years ago Nancy had three back surgeries to alleviate the intense pain she had been experiencing since she was young. The surgeries were not successful and as a result of the excruciating pain, Nancy was forced to leave her job at the College of William and Mary in 1997. She was also forced to end her volunteer work at a regional prison where she counseled inmates on their futures and how to lead a better life outside prison.

However, it was complications from diabetes that posed a number of health problems this past year. Nancy has been living with diabetes for 41 years. She is one of the estimated 23.6 million Americans living with this life-threatening chronic illness that affects the body's ability to use blood sugar for energy. One of the leading causes of disability in the country, the number of people diagnosed with diabetes in the United States continues to rise at an alarming rate, according to the Centers for Disease Control and Prevention (CDC). While Nancy successfully manages her illness, she does suffer from congestive heart failure and has experienced several complications throughout the years.

Toward the end of 2007, Nancy began having some foot ailments which were treated with oral antibiotics. Complications from a foot infection led to the amputation of Nancy's left big toe in January 2008. Following the surgery she was given oral antibiotics to fight infection, but shortly thereafter, she developed another infection where she was prescribed a course of intravenous antibiotics. Nancy was told that she would need to undergo her infusion treatments in the hospital as an outpatient because Medicare would not cover home infusion therapy. "I was stunned and angry to say the least," says Nancy. "I did not know how I was going to do it. Between my surgery, my back and my heart, I was barely mobile. I needed assistance getting in and out of a car. My only caregiver, my husband, was sick," she adds. "As retirees, we were on a fixed income. We could not afford home infusion, so I had no option but to go to the hospital each day."

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Despite the challenge, Nancy and Bill made the trip to and from the hospital each day. "It was very difficult for both of us. It took more than three hours of our day each day. We were exhausted. I felt so bad for my poor Bill who had to drive me to the hospital carrying his oxygen tank. I was in so much pain that at times I did not even remember going to the facility. I certainly would not want to experience that again," says Nancy. "Medicare should consider the needs of patients and fully cover home infusion therapy."

A few weeks later, the infection was not completely gone and she was prescribed another round of antibiotics. This time Nancy opted to self pay rather than go through the same experience. "It was expensive but well worth. I made the financial sacrifice because I felt my husband and I could not accept what Medicare was offering," says Nancy. "It just doesn't make sense. At a time when every penny counts, Medicare needs to cover home infusion therapy. Getting treated at home is significantly less expensive than a hospital stay and is certainly better for patients.



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William J. Hemming

York, Nebraska

The Heart of the Matter

It's been quite a year for William Hemming. At seventy, he is glad to have his health and to look at life with a renewed sense of self. After fighting for his life this past year, he and his wife Juanita are looking forward to building a new workshop, going to the theatre and most importantly, spending time with friends and family, particularly his children and grandchildren. It seems like yesterday, Bill feared for the worst. "It's still so fresh in my mind that it sends chills up my spine. Life could have taken a different turn. But thankfully, I am here today and once again healthy," he comments.

Bill's health problems started with what seemed like a series of unrelated minor occurrences. One evening in early January, Bill abruptly awoke in the middle of the night sweating profusely. He did not think much of it but he did think it odd that several nights afterward, he experienced the same thing. Coughing and experiencing sinus build-up, he and his wife Juanita figured it was the start of the flu. His doctor agreed and with medicine, the symptoms went away. He felt better.

In February, Bill began feeling pain in the upper part of his shoulders and spine. He went to see his chiropractor because two of his ribs felt out of place. Oddly, the following evening, the same thing occurred when he was getting out of the chair. This time, the pain was severe but with a muscle relaxant, he was able to alleviate the pain.

Then in early March, he experienced tremendous joint pain in the outside part of his left ankle. The ankle appeared a bit swollen and the pain was bad enough that he went to see his doctor. The doctor thought it could possibly be gout, though the pain only lasted for about five days. He wanted a second opinion so he and wife visited her physician. A blood test showed no gout and the x-ray showed no fracture. A visit to an orthopedic doctor who ran an MRI found nothing. Other tests were equally inconclusive. "At this point whatever was going on in my body was a complete mystery," Bill says.

In May, he started waking up in the middle of the night with the chills, sweating, and a fever of 102. On the recommendation of his family doctor, Bill visited a cardiologist who ran a transesophageal echocardiography (TEE), a procedure that allowed his doctor to see the inside of Bill's heart and blood vessels. What they found still astonishes Bill. "They told me there was valve vegetation (an infected mass) of endocarditis growing in my mitral and aortic valves that resembled broccoli head. I didn't know what to think," Bill states. According to doctors, this infection may be introduced during brief periods of having bacteria in the bloodstream, such as after dental work, a colonoscopy or other similar procedures. Bill did recall having a routine colonoscopy in May but realized that this fact does not offer a definitive answer to how he acquired the bacteria. Bill was admitted to the hospital where an infectious disease doctor placed a PICC line that provided him with a strong antibiotic used to treat tough bacterial infections.

Bill was officially diagnosed as having a streptococcus bovis blood infection, a species of bacteria that in humans is associated with endocarditis, an inflammation of the inside lining of the heart chambers and heart. Not quite sure how he acquired the infection, Bill understood the serious bacteria he now had in his blood stream. For the next month and a half Bill went daily to the hospital's outpatient clinic to undergo his intravenous treatments with the hope of removing all the bacteria from his heart's valves.

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Unfortunately, in June, another TEE test showed additional growth in the same area. The IV treatment had not worked and now surgery was required to replace the damaged heart valves. Following surgery, Bill was placed on around-the-clock penicillin therapy for forty-two days. He did two of those weeks in the hospital and the balance of the time at home. "After going through the unthinkable, I just wanted to go home and recover, undergo my IV treatments in the comfort of my own home and settle into my old life and routine," he says. "I quickly learned that Medicare does not cover home infusion therapy and that I would either have to self-pay to infuse at home or undergo treatments in a skilled nursing facility which Medicare covers. Retired and with limited funds, he opted to undergo his IV treatments at the hospital's outpatient clinic. But, two weeks later, he changed his mind and made the financial sacrifice to pay for home infusion therapy. "I just could not stay there any longer. It was depressing. I was worried about acquiring another infection and frankly I just could not tolerate being in an institutional setting any longer," Bill says.

"It does not make sense to me that our healthcare system will incur the high cost of hospitalization, but will not cover the cost of home infusion at a fraction of the cost. "We are wasting valuable taxpaper dollars by allowing this injustice to continue. Home infusion therapy represents a win-win for patients and Medicare alike. Not only are infusion treatments at home less costly than treatments at the hospital, but it is preferred by both patients and their physicians.

Recurrence is a fear I live with every day. But if I am to face a similar health challenge in the future—if I am to require intravenous antibiotics, I hope Medicare will see the cost-effectiveness of home infusion therapy and consider the positive impact to patients' physical and emotional state.



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National Home Infusion Association

Doug Kerkoch

Bend, Oregon

Home is Where the Heart is

Watching one's parents get older is difficult and painful to say the least, but having both parents diagnosed with dementia, is heartbreaking. Doug Kerkoch knows firsthand the difficulty in witnessing the lives of his once vital and very active parents be whittled away by this hideous disease, a tiny bit at a time. Today, as many as 5.2 million people, including 200,000 individuals under the age of 65, are living with the disease. And, as the baby boomer generation ages, it is expected that 10 million will develop Alzheimer's in their lifetime.

Doug is a successful CPA with a wife and grown daughter. He is also executor and guardian of his parents, Frank, 82 and Jean, 81, who both suffer from early-stage dementia. While Doug's parents are marginally capable of self-care with each relying on the other for support, they moved to an assisted living facility during the summer of 2008. "Following their diagnosis, my parents continued to live at their home and were able to care for one another with assistance from my sister and I. However, I began noticing that they were growing increasingly forgetful and confused. They were not taking their medicines correctly nor eating right. Eventually, it became clear to me that my parents needed more care than my sister or I could provide. It was not an easy decision. However, we all agreed that assisted living would extend my parent's independence but in a safe, supportive, supervised setting," Doug says.

Frank and Jean were doing well in their new home. But, in the fall of 2008, Jean began to limp and her shin appeared red and swollen. Following a visit to her physician, Jean was diagnosed with an infection and was prescribed oral antibiotics. However, the infection grew worse and an MRI determined that the infection was on the bone. She was prescribed an eight week course of intravenous antibiotics. Doug's parents have Medicare coverage but while Medicare covers the infusion drugs, the related services, supplies and equipment are not covered. "We were told that Medicare would only cover the infusion treatment for my mother if done at the hospital, a nursing home facility or a health clinic," Doug says. "For my family, none of those options were acceptable," he adds.

"Taking my mother away from her home and her husband to a hospital or nursing home for eight weeks would have had a negative emotional and physical impact on both my parents," Doug says. "They have been married for 60 years and have rarely been apart. They are best friends and have a tremendous love for one another. Despite dementia, their bond is stronger than ever and they continue to support one another as they navigate through their disease. I could not separate them," he adds.

Doug did not want to put his parents through such a painful ordeal. As legal guardian, he made the decision to pay for his mom's home infusion therapy using their savings so his parents could remain together within the safety and comfort of their home in the assisted living facility. "The doctor prescribed daily infusions of one hour. It seemed crazy to transfer my mom, and possibly my dad, from their home to a hospital or nursing home for treatments that only lasted one hour of the day."

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Studies have shown that regular well-established routines and stable familiar surroundings can help to keep the symptoms of disorientation to a minimum for someone suffering from dementia. “I have no doubt that admitting my mom to the busy bustling environment of a hospital would have been frightening and confusing for her to the point that I think it would have been life-threatening,” Doug says.

“The 8-week home infusion treatment cost about \$7000, but it was well worth it. A home care specialist visited my mom daily to administer her medication,” Doug says. “Nothing was more important to me than safeguarding my mother’s safety and well-being and maintaining her humanity and integrity,” he adds. “My mother was fortunate that we were able to pay for the treatments. Countless others do not have the ability to do so. I cannot imagine how difficult it must be for patients and for caregivers who must see their loved ones distressed. The cost of home infusion compared to a hospital stay is significantly less and is better for the patient. As a CPA, Medicare’s unwillingness to cover home infusion therapy makes no financial sense.”



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Diciderio Molina

Lubbock, Texas

The Healing Power of Family

Diciderio Molina or “Desi” as he is lovingly referred to by his friends and family, has had his share of struggles and pain living with diabetes for close to 30 years. However, at 55, he considers himself blessed to be happily married to his wife Becky for 36 years and to have raised two wonderful daughters, Desiree who is married, works, and attends college in Irving, Texas and his youngest Destiny, a freshman in high school.

Desi is one of the estimated 23.6 million Americans living with diabetes, a chronic disease that affects the body's ability to use blood sugar for energy. Diabetes is a life-threatening illness and one of the leading causes of disability in the country. According to the Centers for Disease Control and Prevention (CDC), the number of people diagnosed with diabetes in the United States continues to rise at an alarming rate.

Following his diagnosis in 1979, Desi successfully managed his illness, kept his blood sugar under control and was able to lead an otherwise healthy normal life. That changed in 2001. “Complications from the diabetes resulted in having to leave my job as a car salesman to go on disability. Unfortunately, I was also forced to discontinue my service as an Army reservist,” says Desi. Other health problems emerged. In 2007, complications from a foot infection he had been fighting for three years finally led to doctors amputating Desi’s right leg. Despite the setback and his inability to work following the amputation, he remained optimistic about the future.

In early 2008, Desi was re-admitted to the hospital with a swelling in the knee of the leg that was amputated. Doctors immediately diagnosed it as a bad staph infection and prescribed a prolonged course of intravenous antibiotics. “I was devastated by the news that I had an infection, but I was glad that it was not serious enough to keep me in the hospital. I just wanted to go home, take my antibiotics and get rid of the infection,” says Desi.

Unfortunately, Desi was informed that he could not undergo his treatments at home. “Doctors told me that while Medicare covers infusion drugs, the related services, supplies and equipment are not covered. Home infusions are covered under my service-related benefits but they do not kick in for another few years,” says Desi. “My wife’s insurance was not an option as the home infusion would have cost us well over \$600 per week. With only one income, this was not affordable,” he adds. Desi’s only option was a prolonged and costly hospital stay where Medicare would cover the infusion treatments.

“I was in the hospital for almost two months; too long for anyone to be away from their home and their loved ones,” Desi says. Throughout Desi’s hospitalization, Becky continued to work full-time, maintain the home and care for their 15-year old without the support of her husband. “The hospital stay put a tremendous amount of unnecessary stress on my wife and personally, the experience was demeaning and disheartening. My family is my pillar of strength. I needed to be with them,” says Desi. “Being in the hospital was a waste of time and money. Not only did it put me at risk of acquiring other hospital-related infections, but it cost Medicare \$2000 a day for me to be in the hospital. It does not make sense to me that our healthcare system will incur the high cost of hospitalization, but will not cover the cost of home infusion at a fraction of the cost. I firmly believe that full Medicare coverage of home infusion therapy is less costly, safer for the patient and keeps families together.”



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National Home Infusion Association

Arlyce M. Muncy

Little Falls, Minnesota

Living the “Rest of Your Life” with Courage

The holidays are a welcome time of the year for Arlyce as they represent one of the few precious opportunities she has to visit with her daughter Debbie, her son-in law Kelley and her two grandchildren: eleven-year old Hunter and seven-year old Shayla. Since her husband Glen passed away seven years ago, her sole companion has been Christa, a two-year old Dachshund she adores and who demands most of her free time. While she is very involved in her church, enjoys making jewelry and loves riding her three wheel bike, the anticipation and excitement of seeing her family can be heard in her voice.

However, unlike other families, celebrating the holidays with her loved ones comes with a stipulation. Unfortunately, on Christmas Day, Arlyce and her family will be forced to put on hold the days’ festivities to spend a large part of the day at a local hospital near her daughter’s home in St. Paul receiving infusion treatments that have sustained her life for the past 15 years. She has no choice; without them she cannot survive. Arlyce has short bowel syndrome. Unlike a person with a healthy digestive system, Arlyce’s body cannot absorb enough water, vitamins, and other nutrients from food to sustain life and as a result, must receive needed nutrients intravenously.

At sixty-seven, Arlyce has had her share of health problems including arthritis; Raynaud disease, a disorder that affects blood circulation; a serious staph infection that led to the loss of a finger; and most recently kidney cancer. However, it is her long-term struggle with her digestive system that has affected her life the most. Arlyce recalls having recurring digestive problems in her early thirties. During that time, and throughout her 40s, she carefully watched what she ate and under the care of a local gastrologist tried different remedies to improve her digestive system. It was not until she turned 50 that her digestive problems became unbearable as her body was increasingly unable to process what she ate. Additional tests and scans revealed that her problem was caused by a loss of elasticity in her colon that was preventing the digestion system from working properly. Following her doctor’s recommendation, Arlyce underwent surgery to have her colon removed.

Once home, Arlyce and her family hoped for the best--that the digestive problems that had plagued her all those years were gone. Unfortunately, about three weeks later, she felt ill with terrible abdominal pains. Doctors were forced to operate to repair a twisted small intestine and remove the infection that had formed around it. Three surgeries later the infection remained. Her family worried. However, thanks to the persistence of her husband, another specialist was called in to look at Arlyce’s case. The gastroenterologist from Rochester determined that her condition was much more serious and, by the time she was transferred to the facility in Rochester, doctors feared for her life. However, Arlyce went on to survive yet another three difficult surgeries to remove the infection that had spread throughout her entire small intestine. Once again, her family was grateful that her life had been saved. Yet, Arlyce faced a new reality. At the age of 52, she had undergone a life-altering change. Seven surgeries in two and a half months had left her with only three feet of intestine and an ileostomy. “To say my life was changed by this experience is an understatement. When you travel through life on a journey of pain and suffering it will profoundly affect you. However, I was determined to persevere. I was not about to let my condition rob me of my life and freedom,” Arlyce says.

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At the hospital Arlyce learned about managing an ileostomy. She also learned that her now shortened small intestine did not allow any food to stay long enough in her body to provide her with the nutrients she needed to survive. The news that she would require lifelong nutritional support delivered intravenously twelve hours a day was heartbreaking. "My life had totally changed. The harsh reality that I needed to have total parenteral nutrition for the rest of my life was painful; it was news I simply thought I could not handle. However, I had my husband at my side. He helped me through the most difficult of times. Not only did he tend to the cooking, cleaning and other household chores, he bravely cared for my ileostomy when I did not have the strength. He helped me to walk and to climb stairs again and to regain my independence, overall. Not only did he provide emotional support, he certainly earned his nurses cap," Arlyce states. "I miss him terribly. He was my best friend, my soul mate," she adds.

Despite this regrettable change in her life, Arlyce adds that she was grateful for the fact that she could undergo her infusions at night while she slept. "My life was as normal as it could be. I was able to continue working, tend to my home and enjoy some level of freedom," she says. "Later, I felt blessed that while I still required IV fluids to sustain me for the rest of my life, I was slowly taken off total parenteral nutrition which was damaging my liver. While this resulted in only a few less hours of infusion treatments each week, it meant the world to me," she comments. For the next thirteen years, Arlyce lived as normal life as possible, balancing her infusions with her daily activities.

However, at sixty-five, life changed again for Arlyce. She knew this change was coming, but that didn't make it any easier. Having retired from a successful profession in upholstery at 63 she continued medical insurance under COBRA, knowing that once she turned sixty-five, she would have to switch over to Medicare. She knew that moving forward she would be forced to receive her life-sustaining infusion treatments in the hospital as an outpatient because Medicare would not cover home infusion therapy. The alternative was paying out of pocket for home infusion. "As a retiree with limited funds, I did not have the financial resources to personally incur the costs of the medicines and the infusion over the long-term, so I had no alternative but to rely on my Medicare coverage.

Today, at age sixty-seven, Arlyce spends half the day, four days a week, at a local hospital receiving her infusion treatments. "I know I should be there even longer to maximize the benefit of the infusion treatments on my digestive system," says Arlyce. "Ideally, administration should be spread out throughout the course of a seven-hour day, but the thought of having to be in a hospital that long is unbearable, even with the risk of damage to my kidneys from the faster infusion rate."

"Living with this disease is a daily physical and emotional battle. But in spite of the seven surgeries I've endured and the many health scares I have had, until now I always had a sense of relief that I could still have some normalcy in my life by having my infusion treatments at home. Home infusion was a life-saver in more ways than one. It allowed me to be treated in the comfort of my own home and to continue in my day-to-day activities. The fact that I was at home with my family meant the world to me and lifted my spirits. That is all gone now," says Arlyce in her kind and gentle manner. "The fact that I can no longer spend the time I want with my grandchildren breaks my heart." "It is unbelievable how inflexible our Medicare system really is," says Arlyce. "Is Medicare truly looking at the needs of seniors like me or unwilling to change outdated practices that no longer serve the needs of older Americans?" Case in point: Last year Arlyce had difficult surgery to remove a cancerous mass from her kidney. Still weak after returning home from the hospital, she submitted a request to Medicare to see if an exception could be made that would allow her to receive her infusion treatments at home for two days. Her request was denied. "I was dumbfounded. I was told that I must go to the hospital to receive my infusions or do without," says Arlyce. "These fluids sustain me—keep me alive. I was weak and in tough shape. However, I had no alternative but to get myself to the hospital. I was hurt and frustrated over a system that did not look at me as an individual and frankly did not care about my health."

"It does not make sense to me that Medicare will incur the high cost of hospitalization, but will not cover the administration of the treatments at home and at a fraction of the cost. By not covering the administration of intravenous medicines at home, Medicare is placing an unnecessary burden on seniors such as me, forcing us to be treated in hospitals or nursing homes when it is safer for us to be at home," Arlyce says.

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"I've have had my share of health scares but the precariousness of my situation as it pertains to infusion therapy is unquestionably a great source of concern. Many times I feel powerless. I am getting older. I worry about the day when I will not be able to get to the hospital for my infusion. What will happen if I am unable to drive in a severe snow storm? What will happen if my car breaks down or I simply cannot physically make it to the hospital? "I have no family here; no true support system. It is shameful that older Americans cannot get the care we need and deserve. No one should be denied the right to live their lives to the fullest.

"The happiest moments of my life are those spent with my loved ones. My life has changed such that I am unable to visit with my grandchildren like I did before. This year, it will be hard to celebrate Christmas when I will have to spend a great deal of the day in a hospital. What kind of memories will my grandchildren have? As someone who is experiencing firsthand the negative impact of the current legislation, I cling to the hope that I can help create change. Home infusion is not only more cost effective but it is also better for the individual and their families. It does not get any simpler than that. We need to ensure that legislation to modify the current Medicare laws is achieved.



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Linda J. Olson

Perrysburg, Ohio

Embracing Life's Challenges: Living with Short Bowel Syndrome

Three times a week Linda Olson spends a large part of her day at the local hospital. At age 62, Linda can think of better places to be, but the life-saving IV hydration therapy she undergoes for four hours each of the three days has helped her remain healthy and battle the recurring infections she's endured since developing short bowel syndrome. "Hydration therapy has been a life-saver. It's given me a renewed sense of hope," Linda says. "I am incredibly happy and grateful that it is working and enabling me to finally regain a sense of normalcy in my life."

Chronic gastrointestinal disease can be physically and emotionally devastating, yet for more than forty years, Linda has managed the complexities of short bowel syndrome and ulcerative colitis before that, with a positive attitude and tremendous courage. Her health issues started at the young age of twenty-two. Newly married, happy and in love, she had the hopes and dreams every bride envisions when starting a new life as a couple. Yet, for Linda, the honeymoon phase didn't last very long.

On one otherwise uneventful day shortly after getting married, Linda felt agonizing pain in her abdomen. She felt nauseous and could not eat. The pain grew progressively worse throughout the day. When the pain became unbearable, she decided it was time to go to the emergency room. She knew that diverticulitis ran in her family, but she refused to accept the fact that the horrible pain she now felt was related. At the hospital, she was diagnosed with a severe case of ulcerative colitis. While the cause of ulcerative colitis is not fully understood, about 700,000 people in the U.S. have this auto-immune inflammatory bowel disease.

Linda underwent emergency life-saving surgery to remove part of her diseased small intestine, resulting in the establishment of a permanent ileostomy. The surgery may have changed Linda's life, but she persevered. "The realization that my body and life were changed forever was a struggle," Linda says. "But, I was not about to let the fact that I had an ostomy impede anything I wanted to do in life." Linda was thankful to be alive and found the strength to adjust to the changes to her life. Sadly, her husband could not. They divorced and Linda was once again confronted with tremendous loss and change, yet she refused to give up hope for a better life. Linda courageously planted the seeds of a fresh new life in Dallas. Though she continued to struggle with her health, there was a silver lining. Not only was she closer to family but she eventually met Darwin, her true partner in life. "My husband has been my rock of Gibraltar. I have no children of my own but I have been blessed with a wonderful man who has supported and comforted me and whose strength, compassion and encouragement have helped me to cope through many difficult days."

Through the years, Linda experienced life-threatening complications from short bowel syndrome including obstruction of the bowel and infection. In Linda's case, the blockages she experienced were due to post-surgical adhesions that had formed from her initial surgery. She was in and out of hospitals fighting one infection after another with extended stays that lasted 1-2 weeks at a time. While doctors attempted to treat Linda without surgery, eventually there was no other recourse

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but to perform a bowel resection. This helped, but in the years to follow, continued obstructions and infections led to multiple surgeries and additional resections.

After her last surgery in 2005, Linda's significant loss of small bowel now required a specific dietary plan to stay healthy and to survive. So, for two years she was placed on total parenteral nutrition (TPN). "It was a difficult experience, and I feel for those who depend on it long-term for their survival," she says. Although Linda was able to wean off the TPN, maintaining adequate fluid levels became a permanent medical condition. Her physician prescribed a treatment regimen of infused hydration therapy that to date has managed to keep infections at bay. The hydration therapy began on an as needed basis, but has progressed to 7 liters a week in order to maintain adequate fluid levels. While hydration IV therapy can be done at home, Linda, a Medicare beneficiary, is forced to undergo her infusions at the local hospital. While Medicare Part D covers the cost of the medicine, it will not cover the supplies or equipment required to undergo infusion therapy at the home. Medicare will only cover infusion therapy if administered at a hospital or skilled nursing facility. "My physician, the one person who truly understands my medical condition, has contacted Medicare numerous times requesting that the infusions be administered at home," says Linda. "He has been denied every time. I have a port, so connecting the IV for the hydration therapy is relatively easy and my husband and I are capable. Yet, Medicare refuses to cover at home therapy.

"It's been a tough journey. My illness has been punctuated by multiple surgeries, hospitalizations, pain, sacrifices, and a body fighting to stay alive. And, now I will require IV fluids to sustain me for the rest of my life," says Linda. I will do what is necessary. However, I have been in and out of hospitals more than any one person should. I would rather not endure another trip to the hospital ever again! It is physically and emotionally draining! Why should I be forced to undergo therapy at a hospital when it is less costly, safer, and more practical to do it in my own home?

As a retiree with limited funds, I do not have the financial resources to pay out-of-pocket for home infusions over the long-term, so I have no alternative but to rely on my Medicare coverage. It does not make sense to me that Medicare will incur the high cost of administering hydration therapy on an out-patient basis, but will not cover home infusion therapy at a fraction of the cost. It's shameful that Medicare is placing an unnecessary burden on seniors such as myself.

"Going to the hospital three times a week for someone in my condition is not a good thing. I experience shortness of breath and fatigue; more importantly, my immune system has been compromised because of this chronic illness." Linda says. "Driving back and forth to the hospital three times a week and staying there for hours on end is not practical, either, nor is it a long-term option. Weather is always a concern. What will happen as my husband and I grow older or when my husband or I can no longer drive? What if one of us gets sick? Will I be forced into life in a nursing home, which I so desperately want to avoid? These are some of our concerns.

"I've been through a lot. As retirees, my husband and I are looking forward to enjoying this stage of our lives--free of stress and complications," Linda explains. I called Medicare and asked why I couldn't receive my hydration at home and was told that according to Medicare guidelines hydration is not considered medically necessary. I was shocked. I would like the person who made that decision to go without adequate hydration for a week and then tell me it's not a long-term medical need. It angers me that I am denied the care I desperately need by the same system I worked to support all my life," she says. "For Medicare to really be of value to seniors and the disabled, it will need to reconsider its outdated policy to not cover home infusion therapy. It seems crazy to me that someone in Medicare actually thinks it is preferable to pay for the more costly expense of treatment in a hospital than cover the lesser cost of home infusion."



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National Home Infusion Association

Charles H. Rakes

Mount Vernon, Virginia

Behind a Daughter's Love

Jennifer Waugh smiles proudly when she thinks of her dad. Growing up in Mount Vernon with her mom Hong Soon and her brothers Jason and David, she vividly recalls a strong, vibrant and nurturing father who not only protected and took care of his own family but who was also the father figure looking out for all the kids in the neighborhood. "I love my dad. He was always the dad that assured no child was left behind in a trip to a local carnival or the community pool—so selfless, so caring and so thoughtful." Today, a grown woman with two children of her own, Jennifer continues to take pride in her dad, particularly as he struggles to overcome the debilitating effects of a stroke.

Like most people, Charlie, never expected to find himself face-to-face with a devastating, life-altering event. With a family history of diabetes, and he himself diagnosed with the chronic disease twenty years back, he was not one to take his health for granted. With the watchful eye of his wife of 31 years, Charlie maintained a healthy diet, exercised and was meticulous about keeping his blood sugar under control. But then the unthinkable happened. At 55, Charlie's life changed forever when he suffered a severe stroke that left his speech, memory and cognitive abilities significantly impaired. After the stroke, he was unable to continue his position as a database specialist at a U.S. government agency and was forced to retire. "It was extremely difficult for my dad to accept the fact that he would never work again and that he would be dependent on my mom and others for everyday activities," says Jennifer.

Because her mom's native tongue wasn't English, communications with healthcare providers were at times challenging. It was at that point that Jennifer assumed the role of medical power of attorney for her dad. Despite the loss of independence, Charlie found comfort in time spent with his wife, children and grandchildren. And, with assistance, he is still able to enjoy some of his favorite pastimes including fishing with his sons.

But misfortune would hit once again. Just recently, six years following his stroke, Charlie acquired Methicillin-resistant Staphylococcus aureus (MRSA), a difficult-to-treat infection, in his blood stream. MRSA is especially troublesome in hospitals, nursing homes, and other institutions where patients with open wounds, invasive devices, and weakened immune systems are at greater risk of infection than the general public. Because of the severity of Charlie's condition, additional rounds of intravenous antibiotics were prescribed following the initial treatment to prevent a reoccurrence of the deadly bacteria. During this time, a CT scan ordered by Charlie's doctor demonstrated that he had a mycotic aorta aneurysm. Surgery was performed to debride and irrigate the aortic cavity and to place an endograft to reline the aortic wall. The life-saving surgery was a success. Charlie had a tough few weeks but was discharged from the hospital and prescribed infused antibiotics for at least a month. He was looking forward to going home, expecting to receive his infusions in the comfort of his own surroundings.

Unfortunately, Charlie, a Medicare beneficiary, was informed that Medicare does not cover home infusion treatments at home. His only option was to receive his treatment on an outpatient basis at a hospital clinic or skilled nursing home. While Medicare covers the cost of the intravenous drugs, it does not cover the supplies, equipment and pharmacy-related services needed to deliver the home infusion therapy.

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"My father spent the month fighting—and winning—the battle of his life," says Jennifer. "Coming out of major surgery—bedridden after a month, he was weak and his body was trying to heal. The best place for him was home. Yet, that was the very thing that was denied him. It makes no sense to me that Medicare was willing to pay for a more expensive hospital stay, but was unwilling to cover the costs of infusion at home which was a safer alternative for him."

Home infusion therapy costs about \$200 a day, a fraction of the more than \$2000-a-day cost of an average hospital stay. Realizing the cost-containment potential, almost every private health insurer—Medicare Advantage plans, Tricare and most state Medicaid programs—covers home-infusion therapy.

As a retiree on a limited budget, paying out of pocket was not an option for Charlie. So, despite his weakened state and compromised immune system, he traveled each day with his wife or daughter to receive his infusion therapy at the local hospital outpatient clinic where he was at risk of infection. While challenging, Jennifer took time off work to take care of her dad in the hospital and to be his voice throughout the ordeal. "My dad cannot clearly speak for himself. Yet, I saw the look in his eyes. I know he felt bad about having to unnecessarily put an added burden on my mom and me to care for him in this way."

With this type of infection, combined with the complications of diabetes and heart disease, Charlie faces a future of uncertainty. Doctor's feel there is a possibility that he may need to be on antibiotics for the rest of his life. "This is very concerning now and for the future. I don't want my dad to be in a position where he is at risk of infection because he cannot receive infusion treatments in the safety of his own home."

"There is something incredibly unethical about a health care system that will place someone with a compromised immune system in harm's way. Seeing my dad struggle to get dressed, get in the car and into the hospital is heartbreaking when it could have been avoided. Knowing that my father's is at risk of infection is stressful beyond words. Change must come if Medicare is to truly fulfill their moral and legal duty to protect our elderly and disabled. My dad is a survivor. But, why must he and others like him struggle when it just doesn't make sense! He deserves better. They all do."



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National Home Infusion Association

Stephen E. Reynolds

Butler, Pennsylvania

Bouncing back despite setbacks

Steve Reynolds has had his share of medical challenges, mostly as a result of being diagnosed with lung cancer in 2003. At 53, Steve has a grown daughter and considers himself a proud grandfather to her young son. Looking back at the chain of events that led to his diagnosis, he recalls how he inadvertently learned of his condition. "In 1985, I was diagnosed with a brain aneurysm. It was treated with a surgical procedure where the blood vessel that feeds the aneurysm is cut off with a small, metal clip that halts the blood supply and prevents the risk of future bleeding," says Steve. "In December of 2003, I kept hearing a buzz in my head and went immediately to the emergency room to have it checked. I didn't want to take any chances. It turned out to be a false alarm, but the emergency room doctor noticed I was wheezing and decided to do a quick x-ray. There are no words to convey the shock and despair one feels upon hearing life-altering news. I learn that I had a baseball size tumor in my right lung," Steve recalls. "If it were not for my visit to the emergency ward that day, I would never have known I had this growth until it was too late," he adds.

In 2004, Steve had surgery to remove part of his right lung, and in 2006, a second surgery removed part of his left lung. "Following the surgeries, I was on chemotherapy which was administered intravenously at the hospital. During the past few years, complications have developed including blood clots, sinus infections, and pneumonia that have required extended hospital stays. Each time, I remained in the hospital or was placed in a nursing home for an extended period of time to receive my treatments, even though I had no other medical needs that would require a stay in a nursing facility," he says.

"I have been covered under Medicare since I became disabled six years ago. Medicare covers the infusion drugs, but not the related services, supplies and equipment needed to administer the treatments at home. I am extremely frustrated by the fact that Medicare will not cover home infusion therapy when it makes so much sense to do so. By not covering the administration of intravenous medicines at home, Medicare is placing an unnecessary burden on patients, forcing us to stay in hospitals or nursing homes when it is safer for us to be at home," Steve says. "Unfortunately, I cannot afford the cost of home infusion and therefore have no options. The irony is that home infusion would cost Medicare significantly less than it currently pays to treat patients in hospitals,"

"I have spent countless days away from my home; the longest hospital/nursing home stay was about thirty days--too long to be away from the comfort of one's home. Anyone who has stayed in a hospital or nursing home for an extended period of time understands the depression and loneliness that sets in," Steve says. "The medicines you take may treat your physical self, but your emotional well-being does suffer. Medicare needs to consider the quality of patient care if it is ever going to be a valuable contributor to our healthcare system," Steve comments.



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National Home Infusion Association

Richard S. Rubin

Philadelphia, Pennsylvania

The Healing Power of Home

As a retired pharmacist who dedicated his life's work to working with physicians and other health care professionals to treat and care for patients, Richard Rubin knows the significant role safety, cost and quality of life issues play in any treatment process. "I entered the retail pharmacy business because it allowed me to connect with patients within my community and make a positive impact on their healthcare," he says. "I took to heart my responsibilities as a pharmacist to do all I could to help patients feel better, both physically and emotionally," he adds.

Throughout the years, Richard regularly dealt with the health challenges experienced by individuals who had a disease, but never like this past summer when he unexpectedly came face-to-face with his own illness.

Richard has diabetes, but for the past thirty-years he has successfully managed his condition, maintaining low blood sugar levels and keeping fit. At 77, his health was good and he was enjoying retirement with his wife Gail and seeking every opportunity he had to spend time with his six grandchildren.

Working around the house this past summer Richard noticed his left leg was red and swollen and warm to the touch. Not wanting to take any chances with his health, he visited his doctor right away. He was particularly concerned over a wound on his big toe of that leg that hadn't completely healed. Believing the problem was a blood clot, Richard's physician immediately sent him to the hospital for a series of tests. An ultrasound did find the blood clot, but that was only part of the problem. Further tests found that Richard had a serious case of cellulitis, a bacterial skin infection. Complications arose when additional scans detected osteomyelitis, a bone infection most often caused by bacteria that could have spread to the bone from infected skin, muscles, or tendons next to the bone or have started in another part of the body and spread to the bone through the blood.

After being released from the hospital, Richard was prescribed a six-week regimen of intravenous antibiotics and sent home with a PICC line, a catheter inserted into a peripheral vein that is guided to a central vein, to continue IV antibiotics therapy twice a day at home. Richard was glad to be going home. "Being in the hospital and away from home takes an emotional toll on your mental health not to mention the fear it instills knowing that you are in a hospital full of drug-resistant bacteria and your immune system is at its lowest point."

Richard was glad to be home, but soon after beginning home infusion therapy it became painfully clear that Medicare would not pick up the cost of infusion at home. "It was convenient for my wife and I to undergo my treatments at home, and it felt safer. "But while home infusion therapy at the home was less expensive than treatment at an institutional setting, it was an expense that a retiree on limited funds could not afford to pay. Richard had no choice but to undergo his infusion treatments as an outpatient at an institutional center seven days a week.

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"The fact that Medicare will cover my treatments at a hospital or nursing home, but will not cover the cost of infusion at home, which is significantly cheaper, is absurd," says Richard. "Medicare Part D coverage of the cost of intravenous medicines itself is a good thing, but the fact that it does not cover the infusion supplies, equipment or professional services required to undergo infusion therapy at the home makes the benefit meaningless."

"I have seen firsthand the healing powers recuperating at home can have on the outcome of a patient," Richard comments. "It is unconceivable that someone in my condition, already fighting a serious infection, be placed at such risk at an outpatient clinic," says Richard. It is unethical to put people at risk in harm's way. In the drive to make health care safer, better and more efficient, how is home infusion therapy not the ideal solution? Who is listening to the voice of the patient? Home infusion therapy makes sense. Doctors know it. Patients know it. Major insurance providers know it. Now if only Medicare would see it. Change is needed if Medicare is ever to be of true value to beneficiaries."



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National Home Infusion Association

Jerrel M. Sansbury

Florence, South Carolina

Getting the Most out of Life

Jerrel Sansbury is better known by his family and friends as Mitchell. Mitchell has lived in South Carolina all his life. It was here that he married his best friend's sister, Susan, thirty-six years ago. Now at 56, Mitchell is retired and takes pleasure in spending time with his family and friends, tending to his yard, and playing lots of golf in the plentiful courses that make South Carolina synonymous with golf. Yet, Mitchell is quite different from your ordinary retiree. Mitchell is among the 30,000 adults and children living in the U.S. with cystic fibrosis, a chronic genetic disease, where sufferers have thick mucus clogging their lungs.

Mitchell was diagnosed with cystic fibrosis when he was in his thirties. While this was a major shock and life-changing diagnosis, he has not allowed the disease to take control of him. He effectively manages his disease and is living his life to the fullest. Like others living with cystic fibrosis, Mitchell follows a regular treatment routine to stay healthy and maintain optimal lung function. Medications - inhaled and intravenous drugs - help clear mucus and fight infection. Regular pulmonary tests help to keep his health in check. In 2006, he had a bout with pneumonia that led to a hospital stay. He was prescribed a 14 day course of intravenous antibiotics which he started at the hospital and was able to continue at home. At the time, all medical expenses, including home infusion therapy, were covered through a private insurer. "Home infusion worked out great. It allowed me to be treated in the comfort of my own home and to continue in my day-to-day activities," says Mitchell. "This is certainly the best method of treatment," he adds.

In January of 2009, Mitchell was admitted to the hospital for a course of intravenous antibiotics when a routine check-up determined that his lungs were functioning below 50%. "As in the past, I started the treatments in the hospital with the intent that I would be discharged after 2-3 days and would continue the treatments at home. However, now that I was retired and on Medicare, my situation changed completely," says Mitchell. It was then that Mitchell learned that Medicare covers the infusion drugs but does not cover the supplies, equipment and service needed to administer treatment at home. "My choices were to pay for the home infusion myself or stay in the hospital the full ten days to complete my treatments," says Mitchell.

As he could not afford to pay for the administration of the treatments at home, Mitchell decided to stay in the hospital to complete the antibiotic infusion therapy. "I was very upset. The ten days I remained in the hospital were very difficult. I was depressed, and frankly, I was concerned that I would catch some illness that was floating around in the hospital. Someone with my condition should avoid hospitalization at all costs," says Mitchell. "As it turned out, I did pick up a terrible head cold while at the hospital that I am still fighting a month later. This could have been avoided if Medicare covered home infusion therapy," he says. "It does not make sense for me to undergo treatments in the hospital when I can easily receive my infusion treatments at home. Not only is it better for me, the patient, but it is less expensive for Medicare. With a hospital bill of \$52,000, I don't see how Medicare can continue to misspend dollars that can be better used elsewhere."



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from the Medicare Home Infusion Coverage Gap*



National Home Infusion Association

Gweneth R. Schmidt

Hildreth, Nebraska

The Beauty of Home

"There *really* is no place like home," says Gweneth Schmidt. At seventy-six, Gwen takes pride in having lived her entire life in Nebraska. "It's a wonderful place to raise a family. The air is clean and the people are warm and friendly." Gweneth was born in Bertran and lived in Holdrege with her family until her brothers introduced her at sixteen to her future lifelong partner. Once married, she and her husband Harold made their home in the small village of Hildreth where they raised five children. Gweneth lost the love of her life three years ago, yet the wonderful memories of their fifty-six years together live on in the home they shared and in the faces of their children and twelve grandchildren. To Gweneth, home is the center of her life; the place where she feels most comfortable in the world.

Until recently, Gweneth had no health problems. Despite the need for hip replacement surgery, she had been blessed with good health otherwise. Her first hip replacement seven years ago was successful and without complications. "At the time I remember having some pain in my right hip area. At first I thought I had pulled a groin muscle, but visits to my chiropractor did not help. Gradually, the pain got worse and I was able to do less and less. Walking became increasingly difficult. My chiropractor recommended I see a surgeon who advised me to have a hip replacement. I elected to do so. The surgery went well, rehabilitation went smoothly and I was back home in a few days," she says.

Unfortunately, this past June Gweneth broke her leg at home while getting up from a chair. Doctors believe the fall resulted from a weakening of the bones brought about by osteoporosis. My leg was fitted with a metal plate but during the surgery a staph infection was found in my left hip. I was put on intravenous antibiotics but was told that I would need to have my left hip replaced after I finished with the treatment. Gweneth remained in the hospital for a total of six weeks. "That's a long time to be in the hospital, but I didn't question it. I just wanted to do what needed to get done to rid my body of the staph infection."

Prior to the surgery to replace her left hip, Gweneth was able to come home for eight days in August to celebrate her birthday. After spending so much time in the hospital, you can't imagine how glad I was to be home in the company of my family," she says. "Until you have experienced it firsthand, you can't imagine the feeling of desolation and depression that sets in while you are lying in a hospital bed all day—day after day."

Before she knew it, she was back to the hospital having her left hip replaced. The surgery went well, but doctors prescribed another six-week round of intravenous antibiotics. "After so much time in the hospital, I was hoping to undergo my IV therapy at home. Once I got past rehab, there was no reason for me to stay in the hospital." Yet, Gweneth was told that while Medicare Part D would cover the cost of the medicine itself, it would not cover the infusion supplies, equipment or professional services required to undergo infusion therapy at the home. Medicare would only cover treatment at a hospital or nursing home. "It was upsetting to say the least," she says. "Patients want to be able to heal at home, where they are most comfortable, surrounded by their family and less likely to acquire hospital-based infections that can put their lives in danger. I feared that the longer I stayed in the hospital, the greater risk I stood of getting another infection." Unfortunately,

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Gweneth was not in a position to pay out of pocket for home infusion therapy. "I had only two options: stay in the hospital or drive 45 minutes each way three times a day to undergo infusions treatments on an outpatient basis. In my mind, neither was acceptable." In the end, despite her fears, Gweneth chose to remain in the hospital.

"As the organization charged with promoting quality care for its beneficiaries, Medicare is not truly considering the physical and emotional needs of the patient," she says. It is putting people's lives at risk! It is unthinkable that Medicare is willing to pay double the cost of a hospital stay but unwilling to cover the much lower cost of home infusion therapy. How does this make sense?"



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National Home Infusion Association

Barbara L. Tripp

Bailey, Colorado

Making Smart Choices

Whether it is Colorado's legendary snows or its mild summers, Barbara Tripp takes pleasure in the four distinct seasons that make Bailey, Colorado her ideal place to live. It is here that she has lived for the past 61 of her 86 years and where she has raised five children who have blessed her with eleven grandchildren.

After years of living with joint pain and the associated loss of function that accompanies arthritis, Barbara had hip replacement surgery in 2002. In 2006, she had her right knee replaced and in 2008, a day after her 85th birthday, she went ahead and had her left knee replaced. Until now, each of her surgeries had been successful with no complications.

"On its own, the second knee replacement surgery went smoothly," says Barbara. "It wasn't until the morning after surgery that my troubles began during physical therapy. My stitches broke open, leaving a gaping wound on the knee. The remaining stitches were later taken out, but I was in considerable pain," she says. Barbara was allowed to go home under the condition that she would return for a follow-up visit the subsequent week. Seven days later, Barbara was admitted to the hospital to undergo surgery that would remove a bad infection she had acquired. Barbara remained hospitalized for eight days while she received massive doses of intravenous antibiotics to fight the infection in her knee and save the prosthesis. "When I was discharged, I was told that I would need to continue receiving intravenous antibiotics twice daily for 30 days," Barbara recalls.

She was informed that according to Medicare, she had two choices: she could stay at a nursing home for 30 days while she received her daily infusion treatments, or she could undergo her infusion therapy at the hospital as an outpatient. "Needless to say, neither was an ideal solution," says Barbara. "Someone in my condition is vulnerable to the risk of infection and should not be institutionalized, so staying at the hospital or nursing home were not options I was about to consider. I don't drive and in this small community, transportation is not easily available. Even if someone could take me, going 70 miles each way would be tiring."

Barbara opted to go with home infusion therapy. "As you might imagine, the \$3900 home infusion bill was quite steep, especially since I am retired," says Barbara. "However, despite the financial burden, I felt this was the only way to get the treatment I needed in an environment that was safe and comfortable." Being at home allowed her to garden, care for her cats and dogs, and enjoy the unparalleled beauty of the mountains that surround her home. "All in all, I have no regrets, except one," she says. Through Medicare, people like me do not have the same options as those who can afford private insurance. By not covering home infusion therapy, Medicare is placing an unnecessary burden on patients, forcing us to stay in hospitals or nursing homes when it is safer for us to be at home. It is also unfortunate that precious dollars are being spent in ways that are more costly and that go against our wishes and that of our doctors. There has to be a better way."



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National Home Infusion Association

Susan R. Warshaw

Salt Lake City, Utah

The Love of her Life: A story of perseverance

Susan Warshaw's love and admiration for her husband Keith is unmistakably clear in her voice and in every word she speaks. At 64, Susan sadly lost her husband of 25 years the day after Christmas this past year. He was 84. Keith and Susan's marriage was a true partnership. Their love, respect and friendship endured the test of time and gave them the inner strength they needed to face many challenges throughout their lives together.

A football injury his senior year of high school left Keith paralyzed from the waist down for the remainder of his life. However, Keith refused to let this life-altering injury stop him from living life to its fullest. In many ways he was able to accomplish much more than any able-bodied person. "Keith was an amazing, strong spirited man who achieved all that he set out to do," says Susan. "He was both a savvy businessman and the humblest of humanitarians. He successfully ran a merchandise business founded by his father and later created and operated one of Utah's most unique and memorable retail emporiums. His deep understanding and concern for people with special challenges led him to assist disabled veterans of World War II in recovering from the physical and emotional scars of war, enabling them to live a full and rich life. To say he was a "miracle man" is an understatement," says Susan.

Keith approached his health and quality of life in the same manner--with resolve and steadfast perseverance. Susan was intimately involved in the physical care of her husband and is herself a shining example of overcoming adversity through determination and hope. As a result of his paraplegia, his continuous medical problems caused him to require the need for antibiotics throughout his entire life. He became more and more resistant to most oral antibiotics as the years went by, and in the last several years, intravenous antibiotics were the only effective means of combating infections. "Unlike most patients, my husband was able to pay for home infusions even though it seemed so punitive and discriminatory," says Susan.

"If my husband couldn't have afforded home infusions, he wouldn't have physically been able to go to an infusion facility two or three times a day. His only option would have been to undergo treatments as an inpatient in a hospital," says Susan. "Something, I do not think anyone would want to do if they had the option of home care," she adds. "Hospitals are very dangerous, particularly for someone with a compromised immune system," says Susan. "In the last few years alone, my husband contracted life-threatening infections in the hospital including pneumonia, MRSA, and a full-blown staff infection," "Hospitals are also depressing places that whittle away at your spirit," she says.

"I do not understand why the 'powers that be' at Medicare are not willing to pay for home infusion when it represents a fraction of the cost of what they currently pay to infuse patients in a hospital or nursing care facility," says Susan. Home infusions are safe and simple to administer. There are no needles and the amounts are all measured in advance. "I never required home health care professionals to help with any of my husband's infusions because it was so simple and I couldn't ask anyone to be available at all hours of the day," she adds.

"Seven years ago, I was told by some of the most prominent physicians in the state of Utah that my husband had two weeks to live and suggested that I take him home to let him die. I refused to listen," Susan said. "While there were challenges, I am convinced that my husband's longevity and certainly his quality of life was due to his being able to spend most of his last several years in our home. Everyone should have that choice. Medicare can contribute to healthcare reform by agreeing to cover home infusion therapy; treatment that represents high-quality care at lower costs.



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National Home Infusion Association

James E. Whitehead

Philadelphia, Mississippi

Living with Courage

At 72, Jim Whitehead, owns and operates an insurance agency out of his home. When he is not working, he enjoys spending time outdoors doing yard work. However, in the past few years he has found it increasingly difficult to do many of the things he took for granted such as walking and climbing stairs. Arthritis pain in his shoulders and knees left him feeling physically and emotionally helpless. Living with arthritis takes courage. As the disease progresses, it wears down cartilage that acts like a cushion, resulting in the bones rubbing against each other. "Simple things that most of us take for granted such as walking, bending, and even sleeping comfortably becomes a daily struggle," says Jim. By 2006, damage to both shoulder joints was so extensive that he elected to have surgeries to replace both shoulders. The surgeries went well, so when it came time to consider knee replacements, he did not think twice. In 2007, Jim had total replacement surgery on his left knee. The surgery went smoothly; alleviating the constant pain he had been living with and regaining the mobility he had lost.

A surgery to replace his right knee took place in July of 2008. Once again, there were no complications. However, three months later, Jim started having severe pain in his right knee. "My leg was red and inflamed. I could not move it and the pain was excruciating," he says. Jim was admitted to the hospital and his knee replacement was "flushed out" to clear up the inflammation and possible infection. He was released from the hospital. However, the aspiration procedure did not alleviate the pain nor remove the infection from the joint. One month later, Jim was back in the hospital and this time the diagnosis was *Staphylococcus* or "staph". Implanted materials, like those found in a joint replacement, can allow infections to persist. As a result of the infection, doctors performed surgery to remove Jim's prosthetic joint to replace it with another. While at the hospital, he was prescribed a course of cefazolin once every eight hours for six weeks.

By this point, Jim's difficulty with his right knee had been overwhelming and had taken its toll. He wanted the ordeal to be over. He wanted to go home. "The holidays were coming and the last place I wanted to be was lying in a hospital bed," says Jim. Jim had hoped he would be able to undergo his treatments at home. "Unfortunately, I was told that Medicare would not cover infusion treatments at home. They would only cover treatments done at the hospital. Receiving my treatments at home would demand me paying out of pocket. I was devastated. After all the time I have spent in hospitals with each of my surgeries, I knew the expense of undergoing treatments at the hospital. It was clear that Medicare was spending more money to treat me in the hospital than at home." Jim elected to stay in the hospital because he did not have the ability to pay for home infusion therapy. "By having to stay in the hospital, I was at risk of getting other hospital acquired infections, he says. "The hospital stay was also having a negative financial impact on my business as I was unable to work."

The day after Christmas Jim went home. However, during a follow-up visit in mid-January 2009, his doctor told Jim that the infection remained. He was admitted back in the hospital for surgery to remove the infected prosthetic joint for a second time. Once again, Jim was being forced to undergo another six week round of antibiotic infusion treatments at the hospital, which is still underway. If the antibiotics do their job, Jim will have a new knee replacement in about six weeks. Each day Jim is in the hospital, he faces the challenges of maintaining a positive attitude without surrendering to the disease. "The proposed legislation to fix Medicare's coverage of home infusion offers some measure of hope for people in need of home

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infusion therapy,” Jim says. “It makes no sense to me that Medicare is willing to pay for a more expensive hospital stay, but is unwilling to cover the costs of infusion at home, which represents a fraction of the hospital costs and is safer and healthier for patients,” adds Jim. “As someone who is experiencing firsthand the negative impact of institutional care, I cling to the hope that should I ever need infusion therapy again, I will have the opportunity to undergo treatment in the safety and comfort of my home.”



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Robert L. Zimmer

Rancho Cucamonga, California

Living Life to the Fullest

Sunday night dinner at the Zimmer home is an important family tradition. To Robert and his wife Cathy, spending time with their daughters and their seven grandchildren is truly a blessing and one of life's greatest joys; the other being Cathy's famous mashed potatoes. But for someone like Robert who has lived with Crohn's disease for more than five decades, enjoying a simple pleasure like his wife's mashed potatoes has never really been that simple.

In March 2009, Robert Zimmer turned seventy-three years-old and reflecting on his life, he acknowledges the importance of family. He proudly admits that he has been happily married to his high school sweetheart, Cathy, for more than 53 years. She has been his pillar of strength and a true partner in managing his disease. It was their desire to be close to family that led them from their home in Illinois to Southern California following the end of his military duty.

Robert was only twenty when he experienced his first bout with inflammatory bowel disease (IBD). Back then doctors knew less about the disease so the severe abdominal pain that brought him to the emergency ward one evening was at first misdiagnosed as food poisoning. He continued to have severe abdominal pain, nausea, vomiting and chronic diarrhea and after further testing he was diagnosed as having Crohn's disease.

According to the Crohn's and Colitis Foundation of America about half a million Americans suffer from Crohn's disease, a chronic autoimmune disease where the immune system attacks the intestines and stomach believing them to be foreign objects. There is no known drug or surgical cure for this complicated disease and so treatment options are restricted to controlling symptoms and maintaining remission.

Robert has a severe case of the disease. Although medicinal efforts aimed at controlling the disease have and continue to be made, he has had to undergo six difficult surgeries to remove diseased parts of his intestine. Each time, the surgeries involved long hospital stays that not only put stress on Robert's mental and physical well-being but on his family.

In 2008, he acquired an infection as a result of an abscess in his abdomen. With tremendous pain and a high fever, he went to the hospital where he was treated with antibiotics for one week. Tests determined that while his bowels were diseased, no surgery could be done until the infection had subsided. He was told that he could leave the hospital and continue his treatments at a long-term care facility, nursing home or at home. "In my mind, long-term care was just another form of hospitalization. After being in the hospital for so long, I desperately wanted to come home," says Robert. Another major concern for the Zimmer's was that in 2007 Robert was diagnosed with myelofibrosis, a serious bone marrow disorder that disrupts your body's normal production of blood cells and increases your susceptibility to infection. "Being in an institutional setting is never a good idea for someone like me with a compromised immune system," Robert comments.

"With my wife's medical background, I was confident that she would do a good job caring for my wound and administering my infusion treatments," he adds. However, Robert and Cathy were told that while Medicare would cover the cost of treatment at a long-term facility or nursing home, it would not cover treatment at home.

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"My wife and I discussed our options carefully," says Robert. "As retirees with limited funds, we knew it would be financially difficult to incur the costs of the medicines and the infusion treatments, but in the end we decided going home was the right choice. Unfortunately, this involved using funds that we had set aside for our retirement. It was a bit scary, but we believed that it was the only real option we had, from both a physical and mental standpoint," he adds.

"The fact that I was at home with my family meant the world to me and lifted my spirits. I felt better about my health and regained a sense of normalcy that was impossible while in the hospital," says Robert. While Robert is tremendously grateful to his wife for her willingness to administer around the clock infusions of four medicines needed to treat the abscess, he feels dismay over a healthcare system that denies older Americans and veterans the care that they need and deserve.

"As a patient, the benefits of at-home care far exceed hospitalization. The cost of the home therapy should be covered by Medicare as it is certainly less costly than any hospital or continued care facility," Robert states. "It does not make sense to me that Medicare is willing to cover a more expensive course of treatment at a hospital that includes overpriced room and board but is unwilling to pay the cost of infusion at home which is less costly and safer for someone like me battling infection."

"Living with Crohn's disease is a physical and emotional challenge. As a family we have gone through some very rough times. But with the love, support and understanding of my wife, kids, grandkids and good friends, I have found the determination to fight through this debilitating disease. The financial impact of my condition is unquestionably a great source of concern. I worry about the next time I will need infusion. Affordable healthcare for seniors and veterans is not a privilege; it is a basic human right. As Americans, we need to ensure that legislation to modify the current Medicare laws is achieved."