

# Your Life, Your Choice

*Stories from Kidney Transplant  
Patients and Donors*

Quality Insights Renal Network 4



*Developed through collaboration of ESRD Patients, Transplant Donors,  
ESRD Networks, and the ESRD Network Coordinating Center.*



These are the stories of real kidney transplant patients in their own words. The stories were developed to help address what patients perceive as barriers to receiving a kidney transplant, including age, gender, race or ethnicity, and location.

This booklet was created to inspire hope and encourage optimism for ESRD patients, their family members, and caregivers. It is designed to motivate and empower ESRD patients to explore all treatment modality options, including kidney transplant. The road to transplant begins with referral. We are grateful to the patients and donors who graciously shared their stories.

This booklet was produced by the End Stage Renal Disease (ESRD) Network Coordinating Center (NCC) in collaboration with this ESRD Network:





Hello! I'm a three-year kidney transplant recipient and am feeling just wonderful! My name is Carole, and I live near Harrisburg, PA. I had reflux disease at birth culminating in ESRD when I was in my 60s.

I remember very clearly the time I faced the decision of whether to remain on peritoneal home dialysis or receive a kidney transplant. I was on the dialysis machine ten hours every night, seven days a week. It was a difficult time for both my husband and me, but we depended on our faith in God to see us through. I had an awesome personal relationship with Him, so when transplant was needed I was on solid ground with my faith and trusted in the Lord to help us.

If you are a new potential transplant candidate, be positive and stay positive. Be grateful when a match comes up for you, as this will be your new lease on life. Hold on to your faith in God. Never give up. Believe and picture a happy ending, and it will happen that way.

Each day, I take quite a few pills including, of course, the antirejection pills, but I would do it all again in a heartbeat. What a change in my life - not to be tethered to a dialysis machine with its lights, tubes and bags, and to be able to experience a much higher quality of life. I am a free woman and it's a good feeling. My energy level is way up and I sleep so well at night.

It's great to be able to eat whatever I want with very few restrictions. Today, I look in the mirror and my skin tone is back to normal. Wow! It just doesn't get any better than that for me.

I wrote a memoir about my journey through renal failure and dialysis to a kidney transplant. My story is honestly written (through my darkest days) with my personal thoughts and feelings in journal entries, and it's called *Transplanted to Better Health*. For more information, please check out my website: [www.transplantedtobetterhealth.weebly.com](http://www.transplantedtobetterhealth.weebly.com), or e-mail me at [transplanted44@hotmail.com](mailto:transplanted44@hotmail.com). My book is endorsed by The Kidney Foundation of Central Pennsylvania and can be seen with reviews and purchased on [amazon.com](http://amazon.com), or through me.



—By Carole Fair, Transplant Patient, Quality Insights Renal Network 4



# Joseph

*Pittsburgh Bridge*

The year was 2008 and I was working in a steel plant as a plant maintenance repairman. While getting a physical to return to work after a health problem, the nurse found that I was passing protein in my urine, and advised me to see my primary care provider (PCP) for further evaluation.

So as anybody would do, I went and saw my PCP and explained what was going on. He advised me to see a Nephrologist. So I went and had some tests done and went back for the results. It was then I was told that my kidneys were failing. I was informed that the next step was to have a biopsy of both kidneys.

The results came back a week later with a diagnosis of Focal Segmental Glomerulosclerosis disease (FSGS). I was scared. I was an EMT at one time and thought this was going to be my end. Just when I thought things could not get any worse, they did. My wife had been to her doctor's office and called me to come home right away. She sounded very distraught about something so I asked her what it was and she told me she had cancer. After talking with my kidney doctor about my condition, I felt I was not too bad yet. My wife of 45 years came first. So off we went to my wife's testing, chemo and surgery to the final total clearance. She was free of cancer.

Now we concentrated on my kidney problem (FSGS). By this time, it was very hard to go and work in an industrial plant. During one of my visits to the nephrologist he said that I should really consider getting on a transplant list. But going through life with so many medical problems such as high cholesterol, heart stents (5) and many others, I said enough was enough. Let's just say, my Nephrologist and I got into a very heated debate as to why I did not want to go through with being referred for transplant. So for about an hour we went back and forth on the pros and cons of doing it. My wife and the nurses tried to get me to change my mind. With all three against me, I knew it was not going to go the way I wanted, so I said let's get started with the testing or whatever was needed to be done.

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## *Joseph, continued*

Reluctantly, I took the first step and agreed to be referred. That first step led to the road of getting better and getting on a transplant waitlist in Pittsburgh, PA. The journey continued at the Starzel Transplant Clinic where I received education on all that would need to be done before I can be put on the waitlist.

A set-back occurred on Mother's Day 2009. I thought I had a sprained back. I went to work as usual the next day, but while at work, the pain persisted and I was taken by ambulance to the hospital. Well, it turned out to be a heart attack. I was transferred to Pittsburgh where I had a quadruple bypass done.

After that, I assumed I would not be considered a transplant candidate because I may be a high risk patient now. Surprisingly, after a lot more testing and blood work, I was put on the waitlist for a kidney transplant.

My two sisters agreed to be tested to see if they would possibly be a kidney donor match for me. Surprise, surprise my second sister, Irene Mores, one of a set of triplets, turned out to be a match. When she called and told me we are a match I started to get all my things in life together and wait for the call from my transplant coordinator for the date of the operation.

August 20, 2012 at 7:30 AM was a day that changed my life. We got to the hospital at 5:00 AM and met everybody, then on to being prepared for the operation. This went well and took about five hours, then on to recovery. The next day I tried to get out of bed like I did after open heart surgery but found there were a lot more wires and tubes on me. After five days of listening and doing what was needed to be done, I was discharged to the Family House, a place for family or patients to stay while recovering, only a couple of blocks away from the hospital. After spending a week and a half there I was ready to go home.

Wow, it's been over a year and a half since my transplant. My lab levels are good and even my heart doctor says that everything is going much better now. Currently, I volunteer for the Western Pennsylvania Kidney Support Groups, where we try to spread the word on kidney disease and the resources that are available. The website is [www.wpakidneysupport.org](http://www.wpakidneysupport.org). Feel free to contact me if you have any questions. Now, since turning the young age of sixty-six, people ask me would I have the transplant again. MY ANSWER IS YES!!!

—By Joseph A. Mores, Transplant Patient,  
*Quality Insights Renal Network 4*





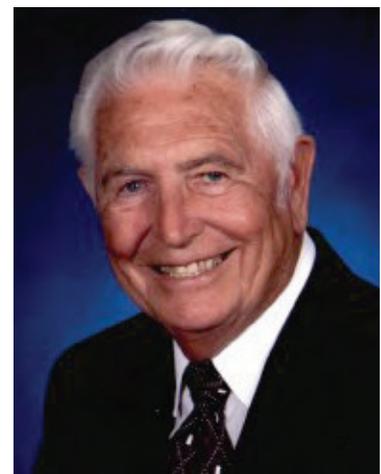
My name is Jack Thomas and I live in Mars, PA with my wife, Annabelle. I would like to share how it came about that I received a kidney transplant on June 18, 2013.

It all began when I went to my primary care physician for a simple annual check-up at age 73. The doctor suggested I have a creatine test. I had never heard of such a test before. The results of this test indicated my kidneys were failing and I would eventually have to go on dialysis. Annabelle and I did not know what dialysis was. After the doctor explained exactly what dialysis was and what was all involved with the treatments, we felt it was something we did not want to go through. When Annabelle asked the Doctor what would happen if I did not go on dialysis, he looked straight at us and said, "Jack would die." We were in shock. As we look back now, we realize this honest answer was the best thing to help us realize the reality we were facing.

Ultimately, I did begin dialysis treatment in 2008 at Seven Fields Dialysis Clinic. I must say it was an overall good experience because of the dedicated nurses and technicians that gave my treatment every Tuesday, Thursday and Saturday. I also knew in my heart that by having a good healthy- positive attitude, it would be best for me as well as for many others sitting around me facing the same problem.

After being on dialysis and getting into a routine, I was thrilled to find out I would not be deprived of enjoying life while I was on dialysis. During the five years I was on dialysis, I was still able to leave for our annual trip to Florida for five months each year. My home clinic here in Pennsylvania made all the arrangements with the clinic in Florida in advance of my arrival. I simply had to walk in for my treatment on Tuesday and on with my life in Florida.

Everything changed on June 18, 2013. On that day, while receiving treatment at the Seven Fields clinic, I received a telephone call from



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## *Jack, continued*

Allegheny General Hospital (A. G. H.). They told me they had a "perfectly matched kidney" from a nine year old boy and I should come to the hospital immediately after my treatment. They assured me I would have a new kidney before the end of the day. I cried when I heard this news. Knowing that someone has lost a loved one but had sacrificially given me another opportunity at living life to the fullest even at my age brought me to tears.

My transplant surgery was on a Tuesday. When the doctors saw my wife and me walking the halls of the hospital two days after surgery had been performed, they were amazed at how well I was doing. I was discharged by Saturday. During my time of recovery at home, I had weekly blood work drawn and sent to the hospital, I had a monthly check up with the doctor at A. G. H. and I began a strict regimen of required medications which I took faithfully. And now, just ten months after my kidney transplant, I'm out mowing the lawn and actually doing everything I did before but just a little slower. (Maybe at age 84 that could be expected.) My wife and I had struggled with the transplant referral steps but with encouragements from the nurses, social workers, and doctors we decided to take a leap of faith. Looking back, we had made the right decision.

I must express my gratitude and thanks for the many prayers from friends and family. It is because of our deep faith in God that He has been with us through this whole journey. Thank you for asking me to share this very vital and wonderful part of my life. I trust this may encourage someone else with a similar situation and experience.

—By John W. Thomas (Jack), Transplant Patient, Quality Insights Renal Network 4



*For additional information and resources  
or to file a grievance, please contact:*



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