

A person is seen from behind, standing in a vast field of bright yellow flowers. Their arms are raised in a gesture of joy or triumph. The sky above is a mix of blue and yellow, suggesting a sunrise or sunset. The overall mood is one of hope and freedom.

# Your Life, Your Choice

*Stories from Kidney Transplant  
Patients and Donors*

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

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This booklet contains real-life stories of kidney transplant recipients and donors, as told in their own words.

The stories were created as a way to share positive perspectives on kidney transplant as a treatment choice. They are designed to motivate and empower kidney patients, their families, and care partners to explore all treatment choices, including kidney transplant.

The booklet does not provide medical advice or information, but rather a first-hand narrative from the patient's perspective.

\* \* \*

Compiled and produced by the  
End Stage Renal Disease (ESRD) National Coordinating Center (NCC),  
in collaboration with participating ESRD Networks.

We are grateful to the transplant recipients and donors  
who graciously shared their stories.





I retired from the post office in 2002, a year after my wife retired from her job in the school system. We planned on travelling—we took cruises and enjoyed our retirement until I started getting sick. We found out that I had high blood pressure. No matter what we did, in 2008, my kidneys failed, and I had to start dialysis.

Dialysis was getting on my nerves. I was washed out after treatments and some days, I could barely make it to my chair when I got home. Being on dialysis for four hours, three times a week, took a lot out of life. We stopped our travel plans; when we looked into taking a dialysis cruise, it was thousands of dollars, and insurance would not pay for Dialysis at Sea.

In the first few months after I started dialysis, the staff asked me if I wanted to be listed for a transplant. I was a little concerned about my age, but I said yes and did everything that they asked. Elsie was unsure; she didn't think that they would give a kidney to someone my age. The people at the transplant center were wonderful. They treated us like family. After all of the medical tests and appointments, in 2013, Elsie was at my side when the calls came. The first call didn't work out, but two weeks later, I had a second call—a young girl had donated organs, and I was given her kidney.

I was transplanted on Tuesday, and Elsie and I were at home by Friday. At age 77, I feel like I've been born again,—it's a new life. Elsie says I am happier too. Now we have time to go out to lunch, go shopping and do all of the things that I was too washed out to do when I was on dialysis. We've been married for over 55 years, and now we are looking forward to a European cruise.

I would recommend a kidney transplant to everybody, it's the only doctor's office that I don't mind going to.

—By Donnie Jacobs, Transplant Patient, IPRO ESRD Network of New York (Network 2)



*Mr. and Mrs. Jacobs*



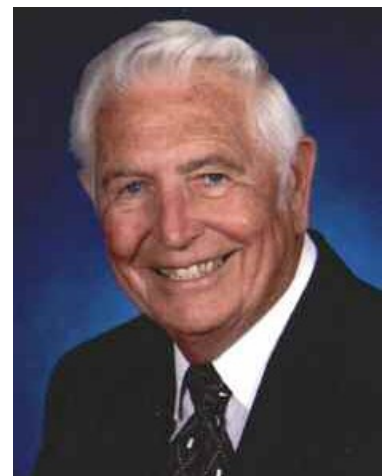
My name is Jack Thomas and I live in Mars, PA with my wife, Annabelle. I would like to share how it came about that I received a kidney transplant on June 18, 2013.

It all began when I went to my primary care physician for a simple annual checkup at age 73. The doctor suggested I have a creatinine 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 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 me my treatment every Tuesday, Thursday and Saturday. I also knew in my heart that having a good, healthy, positive attitude, 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 go 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 (AGH). 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 blood work done weekly; I had a monthly check up with the doctor at AGH; 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 encouragement from the nurses, social workers, and doctors we decided to take a leap of faith. Looking back, we 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*







It was diagnosed with kidney failure during the year 2002. Initially, it was very difficult for me to accept the fact that I had kidney failure. One week prior to my diagnosis I completely lost my appetite and was not urinating regularly, but I was completely unaware of what was causing my symptoms.

One night I could not fall asleep because I had difficulty breathing, and I was gasping for air. My family called the ambulance, and I was taken to the hospital. I remember wearing an oxygen mask and staring into the faces of doctors looking down at me. The doctor in charge told me that I had kidney failure. I was in a state of total shock and denial, telling the doctors that I was brought to the hospital for a breathing problem. How was that related to kidney failure? The doctor explained that he understood my reaction, since he was used to it from other kidney patients. The day after being admitted, the nephrologists brought me literature to read and DVDs to watch so that I could better understand my diagnosis and treatment options. I had to choose whether I wanted to go on dialysis, and if I wanted to do hemodialysis or peritoneal dialysis. I chose dialysis in order to stay alive, but it was a life-changing event!

My kidneys had stopped functioning, and I had strict diet restrictions. My fluid intake was extremely limited, and there was a huge list of foods that I was not allowed to have while on dialysis because my kidneys were no longer able to flush out the toxins that were in my body. Understanding this also made me realize that if I did not decide to do dialysis, I would die shortly since there was no way to flush the excess fluids from my system. All of the new rules and restrictions made me feel miserable and trapped within my own skin.

Dialysis was scary, and I cried every day. Initially I started dialysis when I was in the hospital and then proceeded with my dialysis treatments in a clinic. I was as scared as a rabbit, and shook like a leaf on my first day at the clinic.

While I was in the hospital my niece, Simone, told me that she was willing to donate a kidney to me, and that she would be tested to see whether she was a compatible match. She went to my transplant hospital, and the results came back that my niece was a perfect match!

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## *Marcia, continued*

For a little over a year I had to go three days a week to be dialyzed and for labs to ensure that I was ready for the transplant. Early in the second year of my dialysis, the date was set for my transplant. I received my kidney transplant and now take immunosuppressant medication daily. I visit the transplant clinic three times per year, to go over my medications and to have labs done in order to make sure that the kidney is functioning well. I am now on a normal diet and can eat and drink like a normal person.

If, at any time, I am ill, I visit the hospital in which I received the transplant to ensure that I get treated by the nephrologists, as I am very cautious about taking any prescription medication that would in any way cause an adverse effect to my kidney. My tip for anyone considering transplant is if you are ever in doubt about your care post-transplant, consult with your transplant coordinator; they are a wonderful resource in keeping you healthy!

—By Marcia Richards, Transplant Patient, IPRO ESRD Network of New England (Network 1)



*Marcia Richards and Simone Bowen*







From a very young age I knew that I wanted to help others. I always thought, well, the best way that I could help people was by going into the medical field, because whenever I saw nurses and doctors on television, they really inspired me. This inspiration would later lead me to making one of the best decisions of my life.

I was 22 when I decided to go to the DMV to get my license. When I passed the exam and was filling out the paperwork, one of the questions on the forms was, “Do you want to be in the Organ/Tissue Registry?” I thought about it and said to myself, “of course I would,” so I checked “yes.” Little did I know when I checked “yes” that the opportunity to become a living donor would come just a few years later.

Around the same time that I received my license my aunt, Marcia, was getting very sick. As a family we didn’t quite know what was going on with her. I went to many appointments with her where they ran a lot of tests, and they just couldn’t determine what the problem was. I remember one day I was at work and I received a call from my grandmother, Carmen, who was crying hysterically. I asked her what was wrong and she told me my aunt was in the hospital and that she had been diagnosed with renal failure. At the time I couldn’t process everything that my grandmother was saying. We spoke for a little while longer and that’s when she gave the phone to my aunt.

My aunt made me aware that she would likely need a kidney transplant and that she had plans to go onto the waiting list for a kidney, but that she would have to do dialysis in the meantime. While it may have been a lot to take in at the time, after asking many questions and deep consideration, I decided to donate my kidney to my aunt. I knew that this would be the way to help my aunt to truly “live.” I came to the realization that my decision to go through with the transplant was the right decision for me because as I mentioned before, all I’ve ever wanted to do was to help people, and the fact that this was my aunt’s life at stake made the decision even easier.

Over the course of the following year or so, my aunt and I went through a lot of tests to make sure that I was a match. The initial process was great. Everyone I spoke to was very supportive and answered all of my questions, no matter how difficult they were. They gave me a lot of reading

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## *Simone, continued*

material and although it was a bit overwhelming, they made me feel very comfortable. After completing all the necessary tests we were finally given a surgery date, but I didn't realize that there can be delays and rescheduling of the surgery date.

When our surgery date arrived we ended up having to postpone it because my aunt was extremely sick. I was devastated but also understood why the surgery couldn't be performed. After her health improved, another date was given to us. Our new surgery date arrived, and this time it was me that was not well. They postponed the surgery again, and I did everything that I could to get better quickly. At this point I was emotionally drained. Every part of me just wanted to help my aunt, but I felt like I was holding up the process.

They say the "third time is a charm," and in our case, they were right! We received another date, and although I was a bit excited I couldn't help but think that this date would be postponed as well. Surgery was scheduled for January 22, 2004. My aunt and I had extremely high spirits. I was physically fit, healthy, and ready to do this surgery, and as our surgery date approached I made sure I did everything I could not to get sick, even though the surgery date was during the coldest time of the year.

Unexpectedly, a week before our surgery, my uncle who lived in Jamaica passed away. My grandmother and uncle had to go to Jamaica to take care of his funeral, which left my aunt and me here to go through with the surgery alone. Even though we didn't want them to leave, we understood why they had to.

January 22, 2004 finally came, and that was the day I was able to give my aunt the gift of life! With everything that I had been through to get to this day, I was so emotional, yet extremely excited. I arrived at the hospital and got ready to be prepped for surgery. My aunt was already there from the night before. Something that I wish I had known going into my transplant surgery is that you have to take an epidural to numb your lower extremities so that you won't be in pain. Initially I thought that it was mandatory, but I didn't want to take it so I asked if it would delay the surgery if I went without an epidural. The doctors told me no, so I opted to go through with the transplant surgery without the epidural. I just wish that was better explained to me in the initial stage of the transplant process.

Physically, I was in a lot of pain but I knew it was all worth it because the transplant was a success! Both my aunt and I did great, and today we're both even better! I am just as active as I was before, and I have not slowed down. In fact I think I do more things now than I ever did before. I still travel with my son and enjoy hanging out with my friends and family. I didn't realize that making a decision to be an organ donor would have such a wonderful impact on my life, but if given the option, I would do it all over again!

—By Simone Bowen, *Kidney Donor, IPRO ESRD Network of New England (Network 1)*



*Marcia Richards and Simone Bowen*





Before I was eight years old I was diagnosed with diabetes. Back then, information about the disease was not readily available because so little was known about it. I used glass syringes to administer my insulin. I had to sterilize the syringes in boiling water at least once a week and administer the insulin to myself once a day. My urine was checked to estimate how much sugar was in my system (natural

sugars are necessary to keep our blood flowing), and weekly trips to the hospital for blood work were required. Since then, so many advancements have taken place in all medical aspects, but I have personally witnessed great strides solely with Type 1 diabetes research; it astounds me every day!



Being so young at the time of my diagnosis, I'm not sure what, if any, prognoses were discussed, but I do recall being told that I probably would not live to the age of 50. Well, I have (and then some), through the miracles of modern medicine.

Approximately 30 years after being diagnosed with diabetes, I noticed that I was feeling poorly on a more regular basis. It was a very gradual decline, but I knew enough to inform my doctors.

When I look back at that time frame, my "ex" and I were splitting up; my adored father was dying; and I was working some crazy hours..... no wonder I did not function well! I described it to the medical staff as if I had a perpetual flu, feeling worse every day. "Tired" was an understatement. After sleeping twice as much as usual, I would tell myself each day would be better. I would shower and get dressed, sit down to put my socks and shoes on, only to fall back to sleep for a couple more hours! And my blood sugars were all over the graph. At this point I knew I needed to talk with my doctors, because keeping the truth of how I was truly feeling to myself would only keep my doctors from effectively helping me.

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## *Jane, continued*

After several doctors ordered several tests, I was diagnosed with kidney disease, high blood pressure and high cholesterol. Having been in and out of so many doctors' offices all of my life, I knew to ask questions. Their suggestions were dialysis and to be listed for a kidney transplant. I didn't know a lot about either, and not feeling well made it more difficult to do my research. A new type of renal diet was also recommended, so I tried it. The diabetic diet that I was used to was much easier to maintain, since that was all I had ever followed, although readjusting my diet to limit salt and my water intake (because of retention) was more difficult. For me, getting kidney disease was not due to lack of taking care of myself, because in my situation, I found that strength in maintaining a diet had been worth it.

Dialysis was not fun, but I believed that the alternative was worse. I knew that you had to be really sick to receive a transplant, but I don't recall looking at myself saying "WOW, you're really sick," and the power of positive thinking really helped me through each and every day.

Nothing can prepare us for the unknown, but we are fortunate to live in an age of wonderful medical improvements that are readily available to us. We are all here for a reason and must make the best of every moment and every situation. That is what pushed me to choose transplant, and my hope is that I can now pay this gift forward in order to hopefully help someone else going through a difficult time. You never know who you'll meet or how they can impact our lives, but the least we can do is give every day our all.

—By Jane Andrews, *Transplant Patient*, IPRO ESRD Network of New England (Network 1)





# 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 to 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 (five) 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 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 could be put on the waitlist.

A setback 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.

After that I assumed I would not be considered a transplant candidate because I may be a high risk patient. 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.

On August 20, 2012 at 7:30 a.m., my life changed.. We got to the hospital at 5:00 a.m. 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 if I would have the transplant again. MY ANSWER IS YES!!!

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







My story begins in August, 2006. Because of polycystic kidney disease, I had been seeing a nephrologist for 17 years, when he told me he was retiring because of ill health. He put me into the care of one of the young doctors in his practice. When this doctor saw my creatinine of 4.1, he handed me a list of three vascular surgeons' names and told me to have a fistula put in ASAP—and, “goodbye!”

Needless to say, I was stunned by this news. As my father had, in 1966, been Long Island's first dialysis (PD and HD) patient, I knew exactly what I was in for and decided I didn't want it! So, after a few days of thinking about it, I decided to get a second opinion. At my first meeting with the new doctor, I knew that he was the right nephrologist for me. Therefore, I transferred to his practice and had a number of tests done. Then, the doctor told me that I was a perfect candidate for pre-emptive transplant. He proceeded to manage my medications and diet so that I could stay healthy enough to remain off dialysis, while I searched for a donor.

Next, I signed up with a very well-known kidney transplant center in New York City. There, I completed about a dozen pre-transplant evaluation tests and was finally put on the UNOS list. However, even though I brought six altruistic donors to this center, they were all summarily disqualified. When the last donor, a young girl of 24, was disqualified on the very day I was expecting to receive my surgery date, I knew that, at that transplant center, I would never have my transplant.

It was on this same day that, via online research, I decided to contact a transplant center on Long Island. I sent the transplant surgeon an email, asking if he would see me and evaluate me for a kidney transplant. At his affirmative answer, I made an appointment to meet him and his team on August 26, 2008. Immediately, everything and everyone felt “right.” The team was extremely kind and so knowledgeable that I learned more in that one meeting than I had in over a year at the other transplant center!

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## *Mary, continued*

Everything was handled so professionally and easily that I didn't have to do anything but be examined and answer the doctors' and nurses' questions, in order to fill in my medical history. I was told that I had to have examinations by other doctors, which led to tests being immediately scheduled and soon accomplished.

When all the test results were in and combined with the results of all those done at the other transplant center, the team and I discussed my two donors. These consisted of my last disqualified donor and my sister, the first disqualified donor. It was determined by my transplant coordinator that we would start with my sister, whom I soon brought to meet the team. She was tested and found to be a good match for me, but for the fact that she was 35 pounds overweight. Instead of disqualifying her on the spot, as the other center had done, the dietician and my transplant coordinator worked with her so that she could lose the extra weight, which she did. All her test results from the first transplant center arrived; she had some extra tests, and was then cleared for surgery.

Thus, on February 23, 2009, my sister and I entered the hospital together, and the transplant was done at 7:30 a.m. that morning. I remember joyously hopping up on the operating table, in great anticipation of my operation, and with complete confidence in my surgeon.

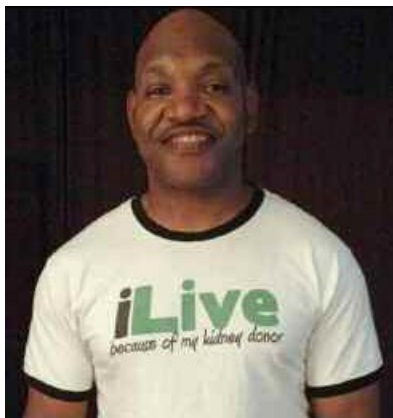
The doctor who invented the laparoscopic kidney-removal procedure, using his own new technique, performed my sister's surgery, and she has only a small scar to mark the occasion of her donation to me.

My care in the hospital was superb. The nurses taught me how to change my bandages, what my medications were for, and when and how to take them. I left the hospital only 48 hours after my transplant, and have not had one problem since!

How thankful I am for this transplant, for it gave me a new life! Each morning, I wake up so happy, to be able to do whatever I want, and to have all the energy I need to do it—something I couldn't say for the first 60 years of my life! I can now eat anything I want and go wherever I please. Since my transplant, I have travelled to Alaska; Phoenix, Arizona; Bermuda; several times to the Caribbean; and I flew to Venice in July for a European cruise. Recently, I joined the Embroiderer's Guild of America to learn new needlework techniques; have learned to knit; and have taken art courses, online courses, and university lectures. My brother, also a transplant recipient, and I attend the Transplant Recipients International Organization meetings each month, in order to learn all the information we can, to continue to keep our kidneys healthy.

Every day I feel so blessed to be alive, energetic, and happy! Whenever I speak to someone who is either on dialysis or soon to be, I tell them what a difference my transplant has made in my life, that I actually HAVE a life, and am not tied down to a machine! Everyone who is in ESRD has a choice to make for the rest of their life. I tell them to "CHOOSE LIFE"—choose transplant and LIVE!!!

—By *Mary Graffeo, Transplant Patient, IPRO ESRD Network of New York (Network 2)*



It was 2011, and I had just had a beautiful new baby girl and landed what I thought was the job of a lifetime, at the time, as a financial advisor. I was under a lot of stress, not sleeping well, and not eating well. I attributed all of this to the new baby and job. On the morning of December 15, 2010, my baby's first birthday, I woke up with a devastating stomachache. I was taken by ambulance to the hospital, where I was diagnosed with pancreatitis. When they took blood tests the hospital noticed that my kidney numbers were very low, but thought it was acute, and attributed it to the pancreatitis. However upon more testing it was realized that it was chronic, and that I was in end stage renal disease (ESRD). Dialysis and transplant were the only options at that point, and my family was devastated by the news.

We started at one transplant facility after hearing very good reviews about their program. Unfortunately, we found that they were disorganized, provided incorrect information, and did not provide follow up regarding next steps. After nearly nine months there with absolutely NO PROGRESS, we decided to move over to another transplant facility. It was like night and day! The team at the second facility was very attentive, very organized, and within three months I was on the waiting list! After a year and a half on dialysis, a living donor came forth and on November 7, 2013, I received my new kidney.

While on dialysis I had days of nausea, listlessness, and bouts of rage and depression. Since my transplant I am back to the person I was 10–15 years ago...full of life and energy! The one piece of advice that I would give would be to do your research on hospitals and transplant teams, so that you don't waste precious time with a team that isn't right for you. Know your options and your rights so that you can surround yourself with a team that will help you accomplish your healthcare goals, and ultimately live the happy and healthy life that you deserve!

—By Roy Graham, Transplant Patient, IPRO ESRD Network of New England (Network 1)





When I first started dialysis back in 1987, I kept coming up with more reasons not to be referred for a transplant than reasons why I should be referred. I was doing great on home hemodialysis, working full-time with no problems. I had seen people come back into the unit following a failed transplant, and they looked like they had been put through the wringer, both physically and emotionally. And frankly, my doctor believed, at the time, that transplantation was a swinging door and that everyone eventually ended up back on dialysis (immunosuppressant medications weren't as effective as they are now either). My sisters repeatedly asked me if they could get worked up to give me a kidney, and I also had numerous reasons for not wanting them to do so. They were my half-sisters, so the match probably wouldn't be that good; I knew that it would be traumatizing for all of us if I rejected one of their kidneys after putting them through the pain of donation; and worst of all, what if something ever happened to their remaining kidney and they had to go on dialysis...how could I have lived with that?

But, three years into dialysis, I could feel that dialysis was taking a bit of a toll on my body. I traveled for my job, and it was getting more tedious to have to arrange transient treatments. My sisters were my helpers on home hemodialysis, and the treatments took a lot of their time, requiring them to be home three to four nights a week. So, when my sisters again approached me about giving me a kidney, I agreed that we should be tested to see if (1) I was a good candidate and (2) they were a good match. My doctor referred us to the University of Mississippi Medical Center in Jackson, MS, where I was told I was an excellent candidate and that my youngest sister Lynda, was a zero mismatch (about as good as you can get). So, the transplant was a GO...it was scheduled for December 7, 1990.

I can't even begin to tell you the difference in how you feel before and after a transplant. The freedom of being able to get away from that machine is liberating and emotionally uplifting, but the

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## *Brenda, continued*

biggest change is the energy that you have. I honestly couldn't remember having ever felt that good before.

Sadly, 11 years after the transplant, the membranoglomerulonephritis that caused my original kidneys to fail came back in the transplanted kidney, and I had to go back on dialysis (and it was devastating to have to deal with losing my sister's kidney). But, this time around, I didn't hesitate when Lisa reminded me that she was the "kidney in waiting" and was ready to give. I received Lisa's kidney in July, 2002, and it has given me an additional 12 years and counting of freedom and good health. I'm now having some issues with this kidney, and don't know how much longer it will last, but I can honestly say that I won't hesitate to get on the list and try for another transplant at some point in the future. As for my sisters, Lynda sees a nephrologist because she has high blood pressure, but her kidney is doing fine, and Lisa has absolutely no health issues whatsoever, so thankfully, both my sisters are doing great!

Looking back on why it took me so long to decide to try transplantation, I just honestly think I was frightened of the unknown, and that's perfectly natural. My advice to anyone who is thinking about getting referred is to educate yourself as best you can. Learn about the transplant process and what happens after the transplant. Knowledge will help take away some of the fear.

*—By Brenda Dyson, Transplant Patient, Network 8*







## Denise

I've been living with kidney disease for about 25 years. I was adopted, so I had no relatives to help. I received my first cadaver transplant in the early 90's and my second in December 2013. My first one lasted almost 20 years, twice as long as the average cadaver donor life span at the time of transplantation back then. I remember the first time simply being asked by my nephrologist if I wanted to go on the list for a transplant right after I started dialysis. No other questions. I answered "yes" and I was on the list just like that...even though I was a cigarette smoker at the time.

Being in my early 20's I really didn't know the scope of it all; I just knew it was what the doctor recommended, so I went for it. The average wait back in the early 90's was one year in California, though I was on dialysis for two, only because of a severe allergic reaction to antibiotics during the first attempt. A year later I received the kidney that would last almost 20 years. I lived a normal life once again, took my meds as ordered, had the energy to work and go to school, received my BA degree, traveled, and worked in real estate. But after the lengthy time of normalcy, the kidney started to fail, and I was soon back on dialysis. After having a transplant for so long, on dialysis, I now knew how really sick I was.

My second referral for transplant was to UCSF. Next I had a transplant evaluation even before I was put on dialysis. I jumped at it. My transplant evaluation this time was an entire day at the transplant clinic at UCSF, talking to social workers, doctors, nurses, nutritionists, and even a financial consultant. They questioned everything, even my reading glasses. I remember when asked the first time if I wanted to be referred for transplant, I said "yes." Well, the wait time for transplant has gone up eight fold in the past 25 years; a donor kidney is a more precious commodity, so they screen people more thoroughly to make sure the person who gets it will truly take good care of it. I "passed" my transplant evaluation and was waitlisted and on dialysis for three years before I received the one I have now. I got lucky. A very rare perfect match.

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## *Denise, continued*

I have my life back; I am working again and have the energy to fully engage. It's an incredible gift! I couldn't imagine not being referred or refusing to be transplanted. I would have demanded it the second time around. If I had one piece of advice to give to anyone considering, or reluctant to be referred for, a transplant it would be this: Would you rather be sick for years on end with serious health complications that go with it? Or would you go for the temporary hump of transplant surgery to have your entire life back and freedom to eat and do what you want? That is your call. Personally, I think it's crazy to stay on that machine feeling sick all the time when you have this option handed to you. Get referred.

—By Denise Mertz, Transplant Patient, Western Pacific Renal Network  
(Network 17)



*Richardson Grove River, Northern CA*



# Lenora

My nephrologist, Dr. Elena Gelfand, talked about transplant from the time of my diagnosis of fibrillary glomerular nephritis. She was clear with me that there was no cure, no effective treatment, and that it would soon lead to complete kidney failure.

My options therefore were: dialysis, kidney transplant, or end-of-life care. I did not consider end-of-life care an option. We discussed, in depth, my options for dialysis and made preparations for that. We briefly discussed transplants but, at that time, I had too much else to think about.

Over the next year she continued to bring up the subject of referral. I considered this as time went by, but I wasn't ready to proceed. I was coping with my illness and really didn't believe that it could get worse. Having been healthy and active for over 60 years, I wasn't sure that I wanted to use the scarce resource of a healthy kidney that could go to someone who was younger. I also did not want to put the wonderful family and friends who offered to donate a kidney at risk. The biggest reason I now believe is that I still did not understand how ill I was and how much worse it would get as my kidneys failed completely.

It wasn't until I started dialysis a year after diagnosis, and experienced that for several months, that I really started to consider it. We finally made the referral about four months in, and it took almost eight months to get on the list. I was blessed in that a year later I received a transplant of a cadaver kidney. My time on the transplant list was short, while most people have a much longer wait.

If I had understood at the beginning, as I do now, that referral is not a commitment to having a transplant, I might have done it sooner. My one piece of advice is to make the referral when it is offered; you don't have to make an actual decision about doing a transplant at that time.

— *By Lenora Coss, Transplant Patient, Western Pacific Renal Network (Network 17)*

# Melinda



At the age of 11, I was diagnosed with acute glomerulonephritis, a renal disease that, after being dormant for eleven years, destroyed both of my kidneys. After plasmapheresis and medication failed, I was placed on peritoneal dialysis. At only 13, my body was too small and too weak to handle this,

so I was put on hemodialysis before I turned 14. At the age of 19, after three failed kidney transplants and what seemed like endless dialysis treatments, hospital stays and physical restrictions, I was placed on the transplant list for the fourth time. At this point I was feeling terribly depressed and alone despite having a wonderful family and emotional support.



I met my future husband, Bill, in July of 1987. It took me almost a month to find the courage to tell him about being on dialysis and even then I could only tell him in a letter. He told me he already knew about me being sick, but didn't know about the dialysis treatments. Amazingly, none of it mattered to him, and we were married on

December 17, 1989. About three months after the wedding the phone rang, and I was told that a donor kidney had been found. I had the surgery and after three prior failed transplants, this kidney worked great. You can only imagine the relief we both felt not having to go for treatment and our shock and disappointment when the kidney failed three and a half years later. I was told that without a living donor another transplant could take over ten years. I had already had four transplants, and first-time recipients have fewer antibodies and are much easier to match.

Several family members stepped forward and were tested, but they were excluded for different reasons. Then, Bill demanded to be tested. They finally did test him because of his persistence and, just like he told everybody, he was an excellent match. The surgery went really well for both of us, and we enjoyed eight years of freedom thanks to Bill's gift. In 2002, Bill's kidney failed and I had to re-start dialysis.

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## *Melinda, continued*

I have always done well on dialysis, just as I have with the transplants. You definitely have more freedom and feel better with a transplant, but recent developments in dialysis also allow a great degree of freedom. Emotionally, the worst part for me was first finding out the transplant was failing, which made me feel like I had failed somehow. Now I know that transplant should be thought of as just a treatment and not a cure.

I am currently on the transplant list and hope someday to have another transplant. With the amount of antibodies that I have, I know that it might not happen, but I do remain hopeful. If I could give one piece of advice to a patient who wants to be referred for a transplant, I would tell them to stay healthy, speak to family and friends about living donors, and find out everything you can about life after the transplant, including insurance, medications and side effects. And, remember, as I stated earlier, transplantation is a treatment, not a cure, but it does happen to be the best treatment out there.

— *By Melinda O'Quinn, Transplant Patient, Network 8*





It happened all quite suddenly and unexpectedly. It seemed like overnight I went from being energetic and active to being fatigued and feeble. I had severe kidney disease, and I was going blind. Through various treatments my vision, thankfully, has been restored.

The decision to begin dialysis was difficult for me. I waited until I really had no other choice.

My doctor had talked with me about transplant. One of my closest friends had a kidney-pancreas transplant several years before. So, I was somewhat aware of the possibilities. However, I knew nothing about the process or protocols for being “referred for transplant.”

When I started dialysis, the social worker said she would contact the “transplant coordinator” if I wanted her to. I said to wait a few months. It turned out to be a year. I really did not understand that I could be referred and not have to act on it right away. I could have “signed up” that first year and taken as much time as I needed to consider what was best for me. I was so ill in the beginning I really needed guidance to help me decide. Perhaps I could have asked a loved one to be my advocate.

I have recently completed all the pre-transplant medical tests. It seems that I have reached a plateau in my dialysis treatment. If a kidney transplant can give me a more energetic and active life, it will be a dream come true. I am ready!

I have learned many lessons through this whole experience. Three lessons stand out here:

Lesson #1 - Ask a lot of questions, and if you are not satisfied with the answers, ask several people the same questions. Eventually, you will get the answer that will be the most helpful to you.

Lesson #2 - Take responsibility and make a conscious choice about your welfare.  
If you do not, someone else will.

Lesson #3 - Find a support system to help you do research or ask questions, if you are not able.

— *by Robin Miller, Dialysis Patient Waiting for Transplant,  
Western Pacific Renal Network (Network 17)*



When I was 20 years old, an autoimmune disease devastated my kidneys. When I started dialysis, all I could manage was getting used to the fact that my life had forever changed. While dialysis is a life-saving treatment, it was hard for me to continue with my college and career plans; I just didn't have enough energy or freedom to pursue my goals.

After a year on dialysis, my nephrologist talked to me about getting referred to the transplant center for a transplant. After I was referred, I honestly do not remember the details of my first evaluation, but what does stand out is the support I received from the transplant team. They know it is a big decision, and I felt they made sure I understood the whole process; moving to the evaluation for transplant, being on the transplant donor wait list and what is involved to prepare myself for a new kidney.

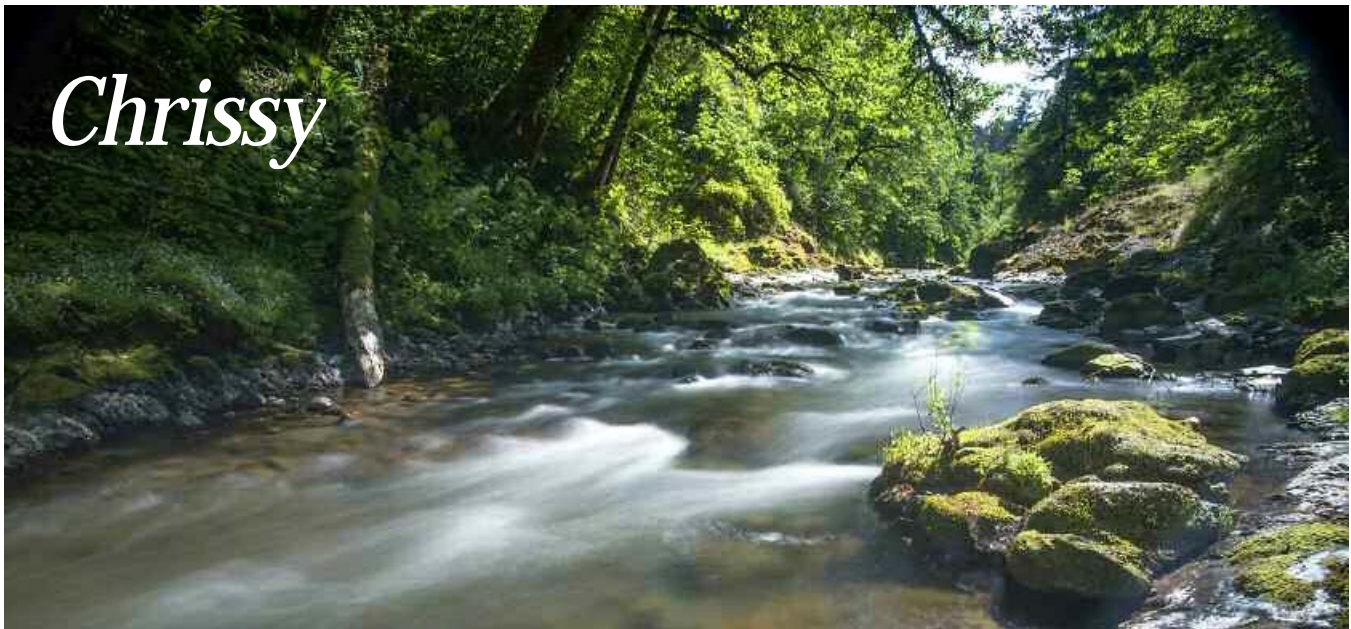
Three years later I received a call from the transplant team; it was one of the most exciting moments of my life! I have no words for how I felt when I received my new kidney. All I can say is that it was one of the best decisions I have ever made. The quality of my life greatly improved, I felt better and I was able to continue with my plans of finishing school, travelling and getting back to work.

A decade later, I needed to return to dialysis, but this time, I did not hesitate to talk to my nephrologist about getting referred to the transplant center for another kidney transplant. While it was difficult beginning dialysis again, I never once regretted my transplant. It afforded me a life I could never have lived if it had not been for my new kidney. The gift of life is also the gift of freedom.

I would like to ask women who are currently on dialysis, if you have not been evaluated yet for a kidney transplant, what are you waiting for? Please talk to your nephrologist; it is worth your time and your life to find out if a transplant is right for you.

—By Shannon Moore, *Transplant Patient, Western Pacific Renal Network (Network 17)*





One would think being born with a hereditary kidney disease would give you plenty of time to prepare for at least the thought of one day needing a transplant. Yes, one would think...

At the age of 31, I went from perfect kidney function with two polycystic kidneys, to very good kidney function with one polycystic kidney, to renal failure when my last native polycystic kidney was removed. I had many people ask how I did it every day, how my husband handled it every day. My answer was always this: "You can choose to fight and carry on, or you can choose to let it beat you." My husband and I chose to fight, side-by-side, every step of the journey.

Our families and friends were nothing short of angels on earth. I am blessed to have two sisters, both of which wanted to get tested, but one was not a blood match. My youngest sister, 21 at the time, already knowing she was a blood match, chose to step forward for further testing. I don't think I've ever admired someone so much. She chose to get tested to save my life and was a match!!! She then chose to share one of her organs with me. To willingly take off work, unpaid, go under anesthesia, have surgery and GIVE me an organ from her body! There just are no words for what this means to me...to anyone who is in renal failure and at the mercy of a machine to keep them alive while they patiently wait for an organ from another human being. No words.

After the transplant, there is a whirlwind of emotions, physical changes, hormonal changes, medications, new rules, etc. all coming at you at lightning speed. The feeling I had when my sister was just taken away from me to go to the operating room is something I will never forget. The feeling of relief when they said the kidney was out, my sister was doing great and the kidney was perfect is another emotional rollercoaster I will never forget. And hearing that the kidney from someone else is producing urine in your body is just awe-inspiring. And let's not forget the excitement of being able to have chocolate, vegetables, milk, cheese, oranges and ketchup again!!! We can't forget about the little things in life.

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## *Chrissy, continued*

My advice for anyone waiting for a kidney would be the following:

- Follow your doctor's orders. To a large extent, your health is in your hands, just as much as it is in theirs.
- Be your own advocate. Keep copies of your records, labs, testing, etc. Report any new symptoms to your healthcare team. Be honest, don't "poo-poo" your symptoms and don't over exaggerate them either.
- Respect dialysis and transplantation. Respect all the patients that have gone before us to make the world of dialysis and transplantation what it is today. Some of us, like myself, would not be here today if it weren't for them.

*—By Chrissy Kihm, Transplant Patient,  
IPRO ESRD Network of New England (Network 1)*





# Dorothy



*Birmingham, AL*

My name is Dorothy Davis, and I am a retired schoolteacher. I taught French at Minor High School in Adamsville, AL for 30 years and for most of those years, I was on some type of dialysis: in-center, home hemo and CAPD. The nine years I spent on CAPD were very productive years, because I was able to take students to France on three separate occasions. I was lucky to have students willing to carry my supplies around Europe!

On June 23, 2001, I received my second kidney transplant. Before my transplant I felt fatigued, especially the nights before and after dialysis. Sometimes I experienced bouts of depression, tired of having to be connected to a machine three times weekly in order to survive. I also felt that I was missing a lot of important events because of dialysis. I felt as if I had only half a life.



Post-transplant, things changed dramatically! The energy level was amazing. I felt ready and willing to tackle all those things I wasn't able to do because of dialysis. Emotionally, I was happier, more optimistic and generally more satisfied with life. I felt more complete, more normal, and I felt as if I "fit in" with everybody else. My second transplant lasted almost 9 years. I re-started dialysis in November of 2010. The decision to be referred for another transplant was an easy one for me to make. Even after 32 years as a kidney patient, I am healthy enough for another transplant, and I am currently multi-listed at three different transplant centers in three different states: University of Alabama at Birmingham Hospital in Birmingham, AL, University of Mississippi Medical Center in Jackson, MS, and Vanderbilt Hospital in Nashville, TN. Multi-listing gives me a stronger chance of being called for a kidney.

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## *Dorothy, continued*

I continue to keep busy as I await the call for my third transplant, teaching adult French classes several times a week and serving as an advocate for my fellow patients at my clinic and in my Network. If there is one piece of advice that I would give to a patient who wants to be referred for a transplant, it's to Be Compliant!! This includes following your diet, taking your binders, not missing or shortening treatments, etc. Following dialysis protocol is a good indication that a patient will also comply with transplant protocol, which can be as onerous as dialysis.

Another thing I have learned over the years, and something I would definitely encourage my fellow patients to do is to try to give back. Nothing gives life more meaning than forgetting about yourself from time to time and remembering to do something for somebody else!

—By Dorothy Davis, Transplant Patient, Network 8





On March 4, 2011, twin sisters Anisha Twymon and Alisha Welch lost both their mother and grandmother to kidney disease. Both were gone on the same day. Six months later, they learned that Anisha suffered from the same disease. When Anisha first found out, she could only think of her mother and grandmother and what had happened with them. She could feel something was wrong, but didn't want to admit that she too could be suffering from kidney failure. When she finally went to the ER on August 20, 2011, she was already in kidney failure and within two to three days, she had the catheter in and had already started dialysis.

Her sister Alisha was in shock. She was very frightened for Anisha because she had all of the same medical problems, such as high blood pressure, that their mother had. During the first year of her dialysis, Alisha stated that they just took the process slowly, learning about their options, but at the end of that first year Alisha told Anisha that they should go get tested to see if she could give her a kidney. Then, Alisha found herself pregnant and they pursued other options, looking at other family members, etc., but nothing worked out. After Alisha gave birth in August of 2012, she went back to work preparing to be her sister's donor.

Alisha got tested to see if she could give her sister a kidney and was told that she would need to lose 20 pounds before the surgery. While Alisha was working on her weight loss, Anisha was enduring dialysis three times a week, having access problems and multiple surgeries. But, she wouldn't let dialysis defeat her, "With all that I went through on dialysis, it never stopped me from being a mother, wife and college student." Anisha attended college from 2006–2013. During that time she had two children and battled kidney disease. She graduated from Talladega College with a BA in Art on May 12, 2013.

The transplant took place on February 21, 2014. Anisha says that the feeling is like nothing she's felt before. She can finally stop watching what she eats and watching her fluid intake. No more dialysis treatments, no more of her arm hurting and no more of having to sit in one spot for over four hours for her treatments. Alisha considered it an honor to be able to give her sister an opportunity at

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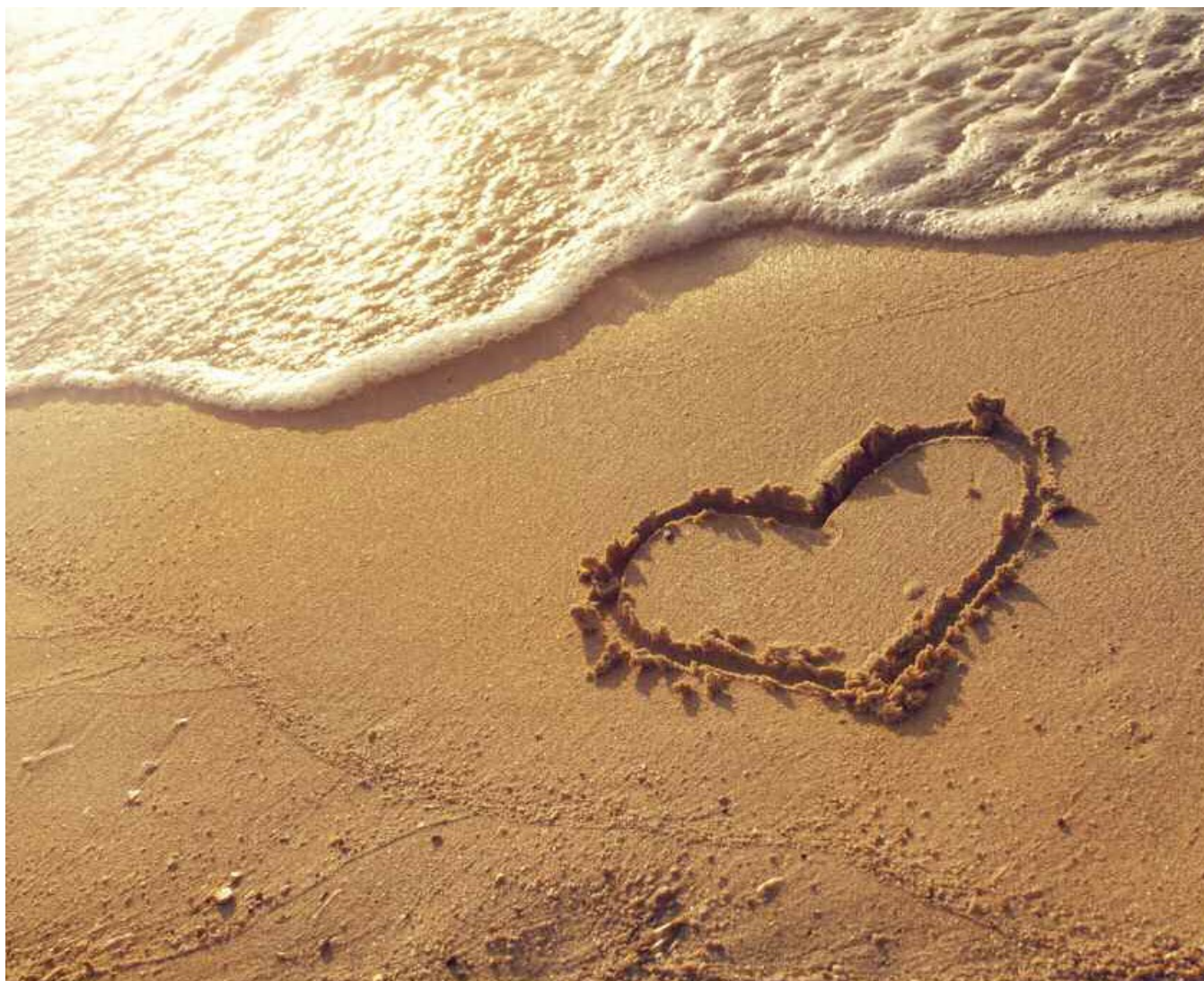


## *Anisha, continued*

prolonged life and believes that she would have done the same for her. “To lose two women in our family and to have a sister diagnosed with the same thing, being the one who could help is a great feeling.”

Both sisters urge other people with kidney disease to have family members get tested if they are interested in giving. Alisha had to lose weight in order for the surgery to take place, but ultimately that made her healthier and also made her able to give her twin sister the gift of life.

— *As told by Anisha Twymon, Transplant Patient, Network 8*







My name is Chris Elrod, and I have been a kidney patient since April of 2000. My kidneys failed, and I lost my vision due to juvenile diabetes. It was an easy decision for me to make to be evaluated for a kidney transplant. You see, I have always had this “never quit” attitude. I was never going to let kidney disease or dialysis get the best of me. I was put on the transplant list a month after starting dialysis.

After many eye surgeries to correct my vision, I was more determined than ever to get a kidney. I stayed on my diet, took my meds, and you couldn’t have paid me to miss a dialysis treatment. I wanted to make sure that there were no marks against me that would keep me from getting a kidney.

I will never forget that day my beeper went off telling me to go to the hospital for a transplant. It was August 24, 2002. My surgery was done at the University of Alabama at Birmingham Hospital, and 12 years later I am better than ever. My labs are great. My life is fantastic! I have a job that I love in dialysis as chief technician/Bio Med for a great company. And I have a wife and two children that I love very much.

If ever the day comes that my kidney gives out, you can bet that I will be back on that transplant list, ASAP. It is a choice that I would make over and over again. My advice for someone who is thinking of being referred for a transplant is to do everything your doctor tells you to do. Compliance is something that we all can get tired of hearing about, but going to treatments and taking your medications doesn’t just keep you on the transplant list, it keeps you healthy so that when you do get the call to come in for a transplant, you are ready and healthy, and will be well after the surgery.



*—By Chris Elrod, Transplant Patient, Network 8*



I was an in-center hemodialysis patient for almost three years from October 1996–August 30, 1999. As you can see I don't remember the exact first date of dialysis, but I do remember the very last date. I was at the dialysis center finishing up my Monday evening treatment when the University of Mississippi Medical Center called the center with the news of a kidney for me. They had tried unsuccessfully to reach me at home and called the center for an alternate contact number. The next day, Tuesday August 31, 1999, I received a wonderful gift from a kind, unselfish and loving family—the gift of a new kidney.

My advice to a patient who is very new to dialysis is to read and research as much information as you can about dialysis treatments and diets to help you feel good and do well. Ask questions about any medications you are given while at dialysis to better understand its purpose and how it helps your care. Just look at dialysis as another form of treatment to help you feel better and be actively involved in your care. Watch your fluid intake, and you should do well; you might feel a little tired afterwards but a couple of hours of rest and you feel better.

As I previously stated, I was fortunate to receive a kidney transplant after 34 months on dialysis. Prior to my transplant, sometimes I would be extremely tired right after my dialysis treatment. However, I went to dialysis after completing at least eight hours at work that day. Therefore, I would go home, get a meal and after a good night's rest, the next day I was fine.

Initially I went through an emotional pity party after being told it was time to go on dialysis. I was depressed and feeling sorry for myself because only three months earlier, I had received a promotion at work. It was a position with more responsibility and one directing the work of second-level managers. I just knew with dialysis my life as I once lived it would be over, and I would have to resign my job. However, my adult son, my friends, and my social worker at the dialysis center helped me to see that my life could be whatever I wanted it to be; the decision was up to me. Therefore, I pulled myself up out of the slump I was in, made arrangements with the dialysis center to take my treatments on the late shift after finishing my work tour and learned to deal with it.

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## *Carolyn, continued*

Tuesday morning, August 31, 1999, I received my kidney transplant and all I could think about when I woke up was, “what can I do to repay this wonderful gift?” After the transplant, physically I had so much more energy and felt good after the surgery healed; I went back to work after six weeks. Several months later, I learned that in the deepest moment of despair a family who lost their 13-year old son donated his organs and gave me and some others a new lease on life. I knew I had to do something to give back and show thanks for this precious gift. Just seven weeks earlier, I had earned a new title, grandmother; actually I’m called MeMe.

For a patient wanting to be referred for a transplant, my advice is to be compliant with your treatment plan at the dialysis center and try to stay healthy. This includes following your diet, taking your meds and showing up for your treatments. Talking to other transplant recipients can also help you to understand what to expect and if transplant is a treatment for you.

For those patients who are withdrawn and not involved in their care, I would say to them: If you think you’re not going to do well, then you won’t do well. Therefore only you can determine what works for you and what makes you feel bad or good. You must want to do well with your treatment and that involves being an active member of your care team.

My approach to life is to live each day to its fullest and enjoy life, but I still take care of myself. Each day I give thanks for what I have and practice that it’s more blessed to give than to receive.



—By Carolyn Price, Transplant Patient, Network 8







# Deborah

I discovered I was in near end renal failure in 2009. I felt as if I had been given a death sentence. My daughter found me the best nephrologist in the valley. I was in Stage 4. After going to my doctor, listening to his every word of advice and care, I had to make a decision—dialysis or transplant.

I put my faith into action and asked my Heavenly Father to lead me; transplant was the way to go. I then went to my doctor and told him what I wanted to do. He then contacted University Medical Center (UMC) to have my name placed on the transplant list. UMC contacted me, gave me a set of instructions, lab work, and tests, all to make sure I was healthy enough for the transplant. I had to attend classes to go over the surgery and how the kidney is placed in your body. They also explained all the medical terms.

I felt so ready by the time my day came. I did end up on dialysis for one month and some days. I was on the transplant list for only eight months—yes, I was truly blessed!

On May 7, 2014, I received the gift of a lifetime, a new kidney. It feels like a second chance at life itself, and I'm so, so thankful. I didn't have a living donor, but I know that God hand-picked this one for me. I'm so grateful to the donor and family for this loving and kind act. Because of this, I plan to become a donor myself.

I know transplants aren't for everyone, but before you count it out, take a real close look. It's life-changing. God bless you all!

—By Deborah B. Tucker, Transplant Patient,  
*Intermountain End-Stage Renal Disease Network (Network 15)*

# Raymond



Raymond Black is from a tiny town located on the Navajo Reservation close to Page, Arizona. He is full Navajo and married to a wonderful Navajo woman. They have three children and grandchildren. One child is currently attending Northern Arizona University in Flagstaff, Arizona. Raymond retired a few years ago, after 30 years at the coal mine in Page, Arizona. His wife is currently working at the local Walmart.

Raymond has been a diabetic for a very long time. Though he was controlling his blood sugar and watching his diet, Raymond's kidneys began to fail in 2011. In 2012, Raymond started dialysis. He completed in-center hemodialysis but transitioned to peritoneal dialysis as it was easier to do at home instead of travelling over 150 miles roundtrip to the closest dialysis clinic.

In 2012, Raymond also became eligible for a kidney transplant, as he worked for months with Mayo Hospital in Phoenix to become a registered candidate. For months, Raymond came to me for his transplant labs as well as his dialysis care. He was so excited that he had qualified to receive a kidney transplant and was looking forward to the day when he would receive the call. Every clinic visit, he expressed his wishes.

When Raymond got the call in the early hours of the morning the first week of September 2013, he rushed down from Page to Phoenix (a four-hour trip) with his wife. His wife called me the next morning to share with me the good news. He is now a proud recipient of a transplant kidney and enjoying his retirement with his wife. Every few weeks we share a phone conversation or he stops in to visit to show me how good he is feeling with his new kidney. He wants to make sure that other dialysis patients know this is an option and to not give up even though the referral and waiting process can be quite long.

I am now proud to say that I have witnessed a patient receive a kidney and be able to live their life to the fullest! I have been honored to provide care for Raymond, as well as call him a friend.

*—By Raymond Black, Transplant Patient, Intermountain End-Stage Renal Disease Network (Network 15), as told to Lindsey Jacobs RN, a home dialysis nurse at DSI Renal Flagstaff*

# Fredrisha



Often times in life, we face many obstacles in which we may feel overwhelmed and like we're drowning. I know personally for me, when I first became aware of my kidney failure I felt lost, completely overwhelmed, and afraid. Although dialysis provided a temporary fix to my kidney failure, it was a kidney transplant that made my life whole again.

I view my kidney as a lifesaver, meaning it is very important to me and I cherish it. My kidney transplant has provided me with a healthy and better outlook on life, but it has also made me feel better, and I will be forever grateful for it. For anyone that is considering transplantation, I am a living witness that it will indeed improve your life for the better and will also give you a completely different outlook on life. A kidney transplant allows you to do the various things that you enjoyed before experiencing end stage renal disease (ESRD) that dialysis may prevent you from doing.

For me personally, I was in high school when my kidneys failed and dialysis prevented me from being able to enjoy various events with my friends. However, with transplantation I was able to resume my normal activities. When considering transplantation, it is very important to remain patient and to remain positive. As with anything in life, good things come to those who wait.

Also, my family played a huge role in my life during the period leading up to transplantation. If possible, make sure to have a reliable and trustworthy support system. Having a reliable support system is very important during this process because it allows you to have people to depend on and support you during the process. Also if possible, try to contact or converse with individuals who have had kidney transplants. They also will be great support systems and will be able to offer real time advice and answer any questions that you may have.

There is never a day that I regret receiving my transplant. Due to the fact that my transplant has tremendously impacted my life for the better, I am an advocate for kidney transplantation, because it provides the best alternative for those suffering from ESRD to have a normal everyday life.

—By Fredrisha Faison, Transplant Patient, *The Southeastern Kidney Council (Network 6)*



# Kennedy



I started dialysis in 2005, and it was really scary at first and very hard to adjust to because end stage renal disease caught me and my wife by surprise. I had recently married, and we had moved into a newly built home just six months prior to my renal failure. It was extremely difficult for me and my wife, but we know that everything happens for a reason. Even now, I look back on all the days I did dialysis and am amazed at how we made it through with our sanity. God is an awesome GOD! We know firsthand that the help of the Lord, family and friends in the dialysis community has helped us cope, understand each stage we've gone through and gotten us past these tests that have been given to us.

I was on dialysis for seven and a half years and on the transplant list for six years before we got the call. The decision to be referred for a transplant was an easy one. I wanted to have the best option that I could find to live a normal, healthy life. I wanted to continue to work and take care of my wife, so when my nurses asked me if I wanted to be referred for a transplant, it was a no brainer. My long awaited call came on Thursday night at 10:30 p.m. on April 25, 2013.

You will be extremely sore after the surgery, but the benefit of not having to do dialysis is worth all the pain. If you have experienced surgery before, you know that your body just needs time to heal. Do not rush the healing process, and follow the instructions of your doctors for maximum benefits. Once you regain your strength you will soon remember how great it feels to be independent and to have energy. You will have to take a lot of medicines, but over time it will decrease somewhat.

If there is one piece of advice that I would give to someone who is thinking about being referred for a transplant, I would simply say "Do it right away!" Contact your social worker for information and talk to your doctor about your options to fully understand the entire transplant process. Then, after you get your transplant, don't take your gift for granted. Show your gratitude for this wonderful gift by living your life to the fullest each and every day!

—By Kennedy Taylor, Transplant Patient, Network 8



*Mike*

My name is Mike Luongo. I was born with a birth defect that caused my kidneys to be irreversibly damaged. When I was only a year old, my parents were informed that at best, I would be starting my young life with 40% kidney function, and one day would need a kidney transplant.

In 2002, I was in my early thirties and my kidneys started to truly fail. I was working full time, playing softball, and had also just gotten married to the love of my life, who was always my main support through this challenging period.

As my kidneys failed, everyday it became more of a struggle to keep up with my life. I had worked as a counselor since I graduated from college, and in my line of work, you need to have the energy to be there for others, but my energy was depleting.

I had to quit my job to start dialysis treatments. I found myself getting more and more tired every day. I had to give up playing softball, which was something that I loved. I had to make compensations for the limitations that were consuming my life. Each day became its own individual fight.

Then the day came when my second life began. On February 19, 2003, I received the Gift of Life from one heroic person. I remember entering the hospital at 6:00 a.m.. I was a little nervous, but very excited to have the transplant. I was with my wife, who kept me strong, even when I was physically at my worst. I never doubted that the transplant would be successful, and I was right not to doubt.

The surgery was not only successful, it gave me the opportunity to achieve more than I ever thought possible. I spent five days in the hospital and a couple more months recuperating. My body adjusted well to the new kidney, and I became stronger than I had ever been, and most importantly, healthier than I had ever been.

I now own my own successful business, and am still happily married to my soul mate. I also volunteer in the community (i.e. singing in my church's choir), and for Donate Life CT because I believe that it is important to give back.

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## *Mike, continued*

When deciding to have the transplant, I found that it was important to remain positive. In fact, I believe that a good attitude is critical to the recovery process. It is also important to realize that there may be some challenges that you will have to face after receiving your transplant, but that the rewards far outweigh these challenges.

I cannot begin to put into words what my new kidney has meant to me and the quality of my life. I believe that the best way that I can honor my donor is to live my life to the fullest. I hope that my experiences can help you as you explore the idea of transplantation. I wish you all of the best.

—By Mike Luongo, Transplant Patient,  
IPRO ESRD Network of New England (Network 1)





# Tunisia



When I reflect upon the last decade of my life, the only way I can adequately articulate what I have endured would be to say that I have experienced the grip of two chronic, life threatening illnesses, debilitating pain that caused me to be unable to work, and emotional anguish that supersedes all conventional comprehension and understanding. I was 23 year old college graduate who was ready to take the world by storm. I had just completed five long, hard years of rigorous training at Meredith College with dreams and aspirations of going to graduate school for flute performance, while taking a professional audition for a principal flute job and university professorship in flute studies. I never got to experience that dream to its fullest. An ugly, five letter word robbed me of what was supposed to be the prime time of my life—my twenties. Instead, it crowned me with pain, fevers, aches, weight loss, rashes, fatigue, and ultimately kidney failure. What was this thing? This thing was lupus.

In 2006, I was diagnosed with systemic lupus, a disease in which the body's immune system loses its ability to distinguish between what's good and what's harmful. Consequently, the body begins to attack its own self. I was unable to live the life of a normal 23 year old woman. In 2008, the devastation reached its climax. During my fourth round of chemotherapy, I suffered a heart attack, went into kidney failure, and started dialysis; all within a 24-hour time period. I literally thought that my life was over.

In the four and a half years that followed, I endured dialysis , experienced a fall that resulted in the fracturing of my pelvis, and suffered the pain and heartache of a would-be donor who, after being worked up for donation, changed her mind about donating and backed out of the process. So to say that the light at the end of the tunnel seemed dim would be a gross understatement. In fact, in my mind, there was no light at all. This would be my life forever. But thank the Lord that his thoughts and feelings were not my thoughts and feelings!

On January 16th of this year, I experienced the miracle of a kidney transplant. The good Lord blessed me to receive a kidney from not only a church member, but from someone who has quickly become a dear friend, like a brother to me—James Watson. His selfless acts of love and gallant generosity

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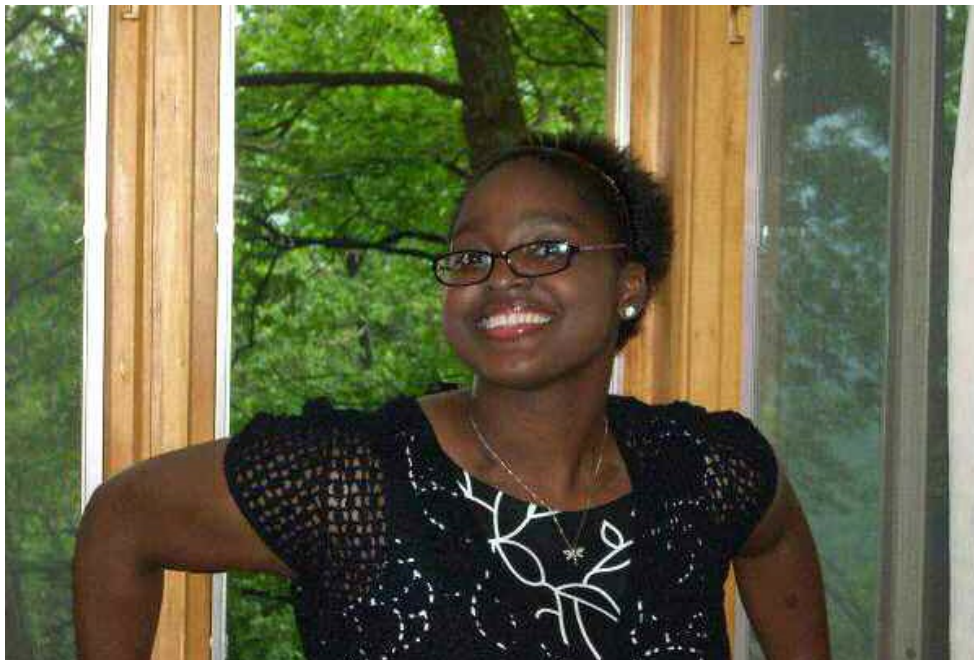
## *Tunisia, continued*

have changed my life forever and for that, I am honored, humbled, and eternally grateful. Because of his self-sacrificing act of love, I am now able to live the life of a normal 30 year old woman. I wish there were more eloquent words for me to express my sincere appreciation, awe, and gratitude to James and his family for the decision they made. All I can say is thank you, and to try to live my life in a way that not only honors and glorifies God, but changes the community, nation, and the world for the better. I plan to do this by entering medical school to become a nephrologist in the fall of 2016.

So I say to all those that are waiting to receive their miracle, your time is coming. Keep fighting, keep praying, and keep pressing forward. Keep your faith strong and remember the words of Jeremiah 29:11:

“For I know the plans I have for you,’ declares the LORD, ‘plans to prosper you and not to harm you, plans to give you hope and a future.”

—By *Tunisia L. Bullock, Transplant Patient,  
The Southeastern Kidney Council (Network 6)*





My name is Leslie Elizabeth Irby. I am a 38-year-old Navajo Indian from a large Reservation in New Mexico. It seems like only yesterday I thought my world was falling apart, when my father was diagnosed with kidney failure due to his diabetes. My father was diagnosed as diabetic about 20 years ago. He never drank or smoked. For years he was on meds to try and control it, which we thought was working. He never missed a day of work, even when he felt his worst.

On February 14, 2012, I attended a doctor's appointment with my family about the swelling of my father's legs and stomach. He hadn't been himself for months but swore to my mother that he felt fine. I will never forget the feeling I felt when the doctor said that more tests needed to be done and that "dialysis" was our next option. I had only heard the word a few times, and it sounded like a solution.

Some solution—after two surgeries to insert a catheter into a main artery to start dialysis, my dad was not my dad. He had no energy, vomited profusely and couldn't even eat. "Dialysis" had literally taken my dad away from me, my mom and my brother; not to mention his seven grandchildren. My dad had always been so strong and tough, but he couldn't fight this. It had broken him, body, mind and spirit.

I sat with him for his first treatment in the hospital, not knowing what I was feeling, just heartbroken for him. It still brings me to tears today. That evening, while my dad ate, then threw up his 1/4 cup of carbs, veggies and Jell-O, his doctor appeared. All I heard was, "Well, we can get you put on a donor list and hope that in two to four years you get a donor." Two to four years, that's not too bad, I thought. The doctor said we might even find a living donor to help within two years. A living donor, I asked? That's all it took! My mom scheduled an orientation with Presbyterian Transplant, and our journey had begun. After hearing all the ins and outs of the whole process, I called Presbyterian the next day and left a voice mail for someone to return my call. No questions asked... I was going to do whatever it took to help my dad.

Our lives revolved around dialysis every Tuesday, Thursday and Saturday. I changed my work schedule

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## *Leslie, continued*

to fit his hours so I could either take him or pick him up. Soon, Mom and I had a routine: she would take him and I would pick him up. I would eat renal dinner every Tuesday, Thursday, and Saturday. My girls had started helping Gram with meals, and they were measuring and eating exactly what their papa was just to be like him; again, bringing me to tears. Meanwhile, I'm having blood drawn, peeing in large orange containers and sitting on pins and needles, hoping I was ok to continue this journey.

Word came that my urine was good—ha, ha, that sounds funny now. Blood work was right on, and a glimmer of hope was in the future. As a precaution I had to have a Pap smear and mammogram. Okay, no big deal, The Pap smear was perfect; mammogram, not too perfect.

"We found a questionable spot in your left breast." Wow, not the words I was hoping to hear. I was sent to a specialist In Albuquerque. In one day I had another mammogram, ultrasound and a biopsy, just to hear that I had a 75% chance of having breast cancer. Here come the tears again. Devastated, my boyfriend and I sat with this so called "specialist" as she told me that I could not be of any help to my father with this diagnosis. I sat with an ice pack taped to my chest from the biopsy, screaming and crying in my boyfriend's arms, feeling like my life was over. Not because I had breast cancer, but because my father wasn't going to get my help. I was truly heartbroken! I couldn't eat or sleep I was on pins and needles for three days. I couldn't even think straight.

Then I received the most amazing phone call. The biopsy came back negative—it was only scar tissue from an injury as a child and I did not have cancer. Ugh, the tears are back! Happy tears, so I called my dad and told him the news. That news finally brought some happiness into a world of heartache.

Next the big blood work-up to see if we were a match. We drove the two hours to Albuquerque, and



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## *Leslie, continued*

it only took 10 minutes for the blood draw. Again, we waited all day, which felt like years. And then came the call , “You are a match”! I was one step closer to what I needed to do, Thank you, God! I was on cloud nine.

I had interviews to make sure I wasn’t talked into doing this huge thing for my dad. I met amazing people on the transplant team and had not one ounce of doubt about the decision I had made. Then it was time for our pre-op tour and meeting with the entire Presbyterian Transplant team.

Overwhelming? YES, but It didn’t change my mind in the least. I WANTED to do this. No questions asked. We got our call that our surgery was scheduled on December 13, 2012. That was the longest ten months of my life. Yes, I said ten months. My dad had to be on dialysis for ten months. It was the greatest phone call I had received during all of this and I couldn’t wait to call my parents and tell them.

I had gone through so many emotions during this time. Happiness, sadness, excitement, disappointment and failure, but I think the strongest rock in this family had to be my mother. She worked so hard to prepare proper meals and gave great pep talks to not only my dad, but to me, about all I was being faced with. Not only did she have a sick husband, she had a daughter who was determined to do what she wanted to help her dad. She is so strong and has put up with a lot and still stands strong.

It is now June 24, 2014, and my dad is the happiest and healthiest he has ever been, and I have a couple scars to show what I did. Not only did I help give my dad his life back, I made the greatest decision to be a living donor and save a life. He is back to being himself, working all day, eating right and playing with his grandkids.

—By Leslie Elizabeth Irby, Kidney Donor,  
*Intermountain End-Stage Renal Disease Network (Network 15)*





I am a 66-year-old Native American belonging to the Washoe and Paiute Tribes of Nevada.

In 2009, I was informed that I had kidney disease and needed to start dialysis. I didn't want to believe that this was happening to me and refused to start dialysis. In June 2010, I ended up in the ICU ward at one of our local hospitals due to high potassium. Finally, my doctor said she could not let me go without treatment any longer. So, I reluctantly began dialysis.

My stubbornness toward treatment was most likely another one of my ignorant decisions. I say this, because, if I would have taken better care of my diabetes and took the disease more seriously when I was first diagnosed, I might not be sitting in a dialysis chair three times a week with an incurable disease.

It was easy to not take the diabetes disease seriously because there was no pain, no real signs of being sick most of the time. If I did go overboard with the foods that I ate, I just took another pill to help bring the sugar level down. Easy, right? Just take a pill or two, or give yourself an insulin shot and you're good to go again—right? Wrong thinking when the diabetes is slowly damaging other parts of your body and you don't even know it!

I have two lovely granddaughters; one is 14 and the other is 8. They are both "A students" and do very well in school. I would like to be around to watch them grow into beautiful, strong, proud young native women, and, if possible to see and meet my great-grandchildren. What a blessing that would be!

I guess my granddaughters are my motive for wanting to be on the transplant list for another kidney. If our elders aren't around anymore because of these diseases, then where are the teachings for our children going to go? We have to be around to teach them before we go on our journey to be with our ancestors. Our ancestors sacrificed themselves for us, and it is our duty to do the same for our future children. That's what keeps our people going!

—By *R. Nutumya, Transplant Patient,  
Intermountain End-Stage Renal Disease Network (Network 15)*



# ESRD Networks

NETWORK 1 (CT, ME, MA, NH, RI, VT)  
**IPRO ESRD Network of New England**

1952 Whitney Lane, 2nd Floor  
Hamden, CT 06517  
Phone: (203) 387-9332 • Fax: (203) 389-9902  
Toll-free for patients: (866) 286-ESRD (3773)

NETWORK 2 (NY)  
**IPRO ESRD Network of New York**

1979 Marcus Avenue  
Lake Success, NY 11042  
Phone: (516) 209-5778 • Fax: (516) 326-8929  
Toll-free for patients: (800) 238-ESRD (3773)

NETWORK 3 (NJ, PR, VI)  
**Quality Insights Renal Network 3**

Cranbury Gates Office Park  
109 South Main Street, Suite 21  
Cranbury, NJ 08512  
Phone: (609) 490-0310 • Fax: (609) 490-0835  
Toll-free for patients: (888) 877-8400

NETWORK 4 (DE, PA)  
**Quality Insights Renal Network 4**

630 Freedom Business Center, Suite 116  
King of Prussia, PA 19406  
Phone: (610) 265-2418 • Fax: (610) 783-0374  
Toll-free for patients: (800) 548-9205

NETWORK 5 (DC, MD, VA, WV)  
**Mid-Atlantic Renal Coalition**

300 Arboretum Place, Suite 310  
Richmond, VA 23236  
Phone: (804) 320-0004 • Fax: (804) 320-5918  
Toll-free for patients: (866) 651-MARC (6272)

NETWORK 6 (GA, NC, SC)  
**IPRO ESRD Network of the South Atlantic**

909 Aviation Parkway, Suite 300  
Morrisville, NC 27560  
Phone: (919) 463-4500 • Fax: (919) 388-9637  
Toll-free for patients: (800) 524-7139

NETWORK 7 (FL)  
**HSAG: The Florida ESRD Network**

3000 Bayport Drive, Suite 300  
Tampa, FL 33609  
Phone: (813) 383-1530 • Fax: (813) 354-1514  
Toll-free for patients: (800) 826-3773

NETWORK 8 (AL, MS, TN)  
**Network 8, Inc.**

755 Woodlands Parkway, Suite 310  
Ridgeland, MS 39157  
Phone: (601) 936-9260 • Fax: (601) 932-4446  
Toll-free for patients: (877) 936-9260

NETWORK 9 (IN, KY, OH)  
**IPRO ESRD Network of the Ohio River Valley**

3201 Enterprise Parkway, Suite 210  
Beachwood, OH 44122  
Phone: (216) 593-0001  
Fax: (216) 593-0101  
Toll-free for patients: (800) 819-3010

NETWORK 10 (IL)  
**The Renal Network-Qsource ESRD Network Strategies**

911 East 86th Street, Suite 202  
Indianapolis, IN 46240  
Phone: (317) 257-8265  
Fax: (317) 257-8291/2120  
Toll-free for patients: (800) 456-6919

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## *ESRD Networks, continued*

NETWORK 11 (MI, MN, ND, SD, WI)

### **Midwest Kidney Network**

1360 Energy Park Drive, Suite 200

St. Paul, MN 55108

Phone: (651) 644-9877 • Fax: (651) 644-9853

Toll-free for patients: (800) 973-3773

NETWORK 12 (IA, KS, MO, NE)

### **Heartland Kidney Network**

920 Main Street, Suite 801

Kansas City, MO 64105

Phone: (816) 880-9990 • Fax: (816) 880-9088

Toll-free for patients: (800) 444-9965

NETWORK 13 (AR, LA, OK)

### **HSAG: ESRD Network 13**

4200 Perimeter Center Drive, Suite 102

Oklahoma City, OK 73112

Phone: (405) 942-6000 • Fax: (405) 942-6884

Toll-free for patients: (800) 472-8664

NETWORK 14 (TX)

### **ESRD Network of Texas, Inc.**

4040 McEwen Road, Suite 350

Dallas, TX 75244

Phone: (972) 503-3215 • Fax: (972) 503-3219

Toll-free for patients: (877) 886-4435

NETWORK 15 (AZ, CO, NV, NM, UT, WY)

### **HSAG: ESRD Network 15**

3025 S. Parker Rd., Suite 820

Aurora, CO 80014

Phone: (303) 831-8818 • Fax: (303) 860-8392

Toll-free for patients: (800) 783-8818

NETWORK 16 (AK, ID, MT, OR, WA)

### **Northwest Renal Network**

4702 42nd Avenue SW

Seattle, WA 98116 Phone: (206) 923-0714 •

Fax: (206) 923-0716

Toll-free for patients: (800) 262-1514

NETWORK 17 (AS, GU, HI, MP, N.CA)

### **HSAG: ESRD Network 17**

1350 Old Bayshore Highway, Suite 328

Burlingame, CA 94010

Phone: (415) 897-2400 • Fax: (415) 897-2422

Toll-free for patients: (800) 232-3773

NETWORK 18 (S. CA)

### **Health Insight**

700 North Brand Blvd., Suite 405

Glendale, CA 91203

Phone: (888) 268-1539 • Fax: (888) 280-8669

Toll-free for patients: (800) 637-4767





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End-Stage Renal Disease  
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