

## Valerie's Story

# It's Never Too Late

*The moment I was diagnosed with a rare disease that affects the kidneys, I knew that kidney failure was in my future. When I turned 72 years old, I was diagnosed with ESRD. It's a good thing I'm not a quitter. Through persistence I learned: you're never too old for a second chance.*

## What was your journey to transplant like?

I have a rare blood type, so I worried it would be hard to find a donor match for transplant. My first transplant coordinator told me that I may be too old for the waitlist, but I was determined to get a different answer. So, I went to my nephrologist and asked about my options. He explained that transplant centers have different criteria and suggested I get on the list with more than one transplant center to increase my chances. That was a real turning point. I got on two centers' waitlists and kept my eyes open for other options.

## How did you get your kidney offer?

It was a miracle I didn't see coming. Six months into dialysis, my nephrologist referred me to Virginia Commonwealth University (VCU) where they were working on a study of diseases that people with increased-risk kidneys may have been exposed to, like Hepatitis C. VCU asked me to be part of a study where I would get an increased-risk kidney. They explained that my risk of infection was low. All I heard was that I would get a kidney and more years with my family. I said, "Count me in!"

## What is life after transplant?

I have a lot more time. Dialysis can be so restricting. I did mine at home, which helped, but it still took hours. Dialysis also really zaps your energy. With my new kidney, I wake up raring to go. I was out of the hospital for three days when I painted my ceilings! It's amazing what this new kidney can do. My high blood pressure and anemia are gone, and I had anemia for 20 years. Sometimes I can't believe that I was ever worried about my age because now I don't even feel my age. Having determination and asking lots of questions got me the kidney I needed and back to the life I wanted.



## What does increased-risk really mean?

Kidneys are called increased-risk if they come from a donor who may have been exposed to HIV, Hepatitis B, or Hepatitis C. The risk of getting these diseases is low and consenting may shorten your time on the waitlist.

“I’m living proof.  
Second chances are  
always possible.”



### Get a Second Opinion

It’s important to get multiple opinions when making a decision this important. Sometimes it’s too easy to trust the first opinion and not ask enough questions. Talk to your nephrologist and multiple transplant centers.



### Call People Who Care

I’m part of a big military family that’s scattered all over the US. Even though we live far away from each other we talk on the phone and email all the time. They’ve been an incredible support.



### Participate in a Medical Study

Are there any academic medical clinics or research centers near you? You could qualify for a clinical trial, where you can contribute to research that will help you and others. Ask your doctor or nephrologist or search for kidney trials online.



### Join a Support Group

Other patients are your greatest resource. They understand what you’re going through, can share stories, and give advice. Ask your care team to connect you to local or online support groups for ESRD.



Susan's Story



## What is high-KDPI?

The Kidney Donor Profile Index (KDPI) measures how long a kidney is expected to function and its risk of rejection. High-KDPI kidneys may function for shorter amounts of time, but consenting to high-KDPI kidneys may get you off the waitlist sooner. Talk to your doctor about if high-KDPI could be right for you.

# Finding the Perfect Match

*I realized early after I was diagnosed with ESRD that dialysis was going to be tough. I knew immediately that I wanted a kidney transplant as soon as possible.*

## How did you learn about ESRD and transplant?

My family has always been susceptible to cysts. When I got cysts on my kidneys, it was no surprise. While on dialysis I had several fistula infections and started feeling like I was constantly at war with my own body. It was exhausting. Even simple things had become so hard. I'd have to sit down for 30 minutes after making the bed or doing the dishes.

I knew dialysis was going to be hard, but I didn't know that it was going to be so complicated. I needed a better option. I talked to my doctor and started reading articles from sites I trusted, like the National Kidney Foundation and Johns Hopkins University Hospital. I learned so much about transplant and discussed next steps with my doctor. I knew transplant was my chance to get back to a normal life.

## How did you get the right kidney?

The first time I got the call, I was told the donor was around 40 years old and had no major medical issues. It seemed like the perfect kidney for me. But it wasn't meant to be. We had to stop the surgery halfway through because I had an allergic reaction to a serum, which rarely happens. So, I was back on the list, waiting for what I knew would be the right kidney.

Two months later, I got a call. This time the donor was 64 and the kidney had a "high-KDPI" percentage. But high-KDPI kidneys still can work well, and my doctor really wanted this kidney for me. It was a functional kidney with a good filtration rate and that's what I needed! I trusted my doctor and decided to go for it. It was probably one of the best decisions of my life. Surgery went perfectly and it's been smooth sailing ever since.

## What is life like after transplant?

When I was healing after transplant surgery, my doctor said, "You're making this look too easy!" That wasn't my doing. It was the right timing; it was the right kidney. Now I have so much energy. Forget having to rest after making my bed, now I can clean my whole house at once! This kidney—even though it was high-KDPI—gave me my life back.

“Don't dismiss a high-KDPI kidney. It could transform your life.”



### Ask and Research

I could have decreased my anxiety if I just asked more questions. Talk to people who can guide you, such as other patients who've had a transplant, and the staff at your local transplant center.



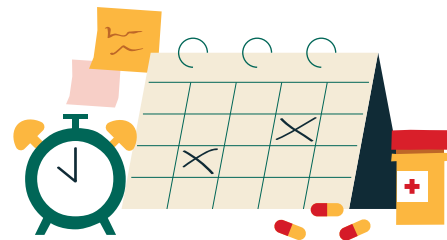
### Cook Kidney-Healthy Food

When you have a strict dialysis diet, cooking your own food gives you control over how you treat your kidneys. Learn some simple kidney-healthy recipes that you love.



### Listen to Your Body

I have to push myself to exercise. I heard my body was telling me it needed to move more. Get up and walk. You'll feel much better.



### Create a Sustainable Routine

Work with your care team to figure out a health routine that is sustainable for you to meet your health goals. Learn which rules are most important. Most of all, stick with it. You can do it!



## Angela's Story



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Talk to your doctor about if high-KDPI could be right for you.

# Knowing My Options

*I watched my mother struggle with dialysis. So, when I got diagnosed with kidney failure, I knew that dialysis was not a good long-term solution. I was determined to find a better treatment.*

### What was life like before dialysis?

I have a family history of kidney disease. The odds I'd face it myself were high. When my mother was going through dialysis, I saw how difficult it was for her. She was always so tired and spent so much time at the dialysis center. I have an active lifestyle and it was important for me to maintain it. My goal from the beginning was always to get a kidney transplant.

### How did you feel when you received your transplant?

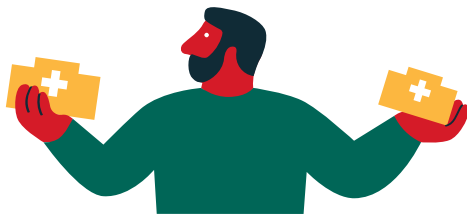
My husband and I have spent our whole lives traveling. We're also avid bikers and love playing tennis. I'd honestly spend all day outside if I could. I knew a transplant would let us stay active, so I started looking into it. I visited transplant centers in nearby states to compare waitlists. I was 68 when my kidneys failed, so I found a center with the widest criteria for accepting kidneys, like high-KDPI, and got on the waitlist.

The first time we got a call we rushed to the hospital. Just before the surgery, the kidney stopped working. I took all the right steps but didn't prepare myself for that! I was so discouraged. My husband reassured me that there was a kidney out there for me and it was just a matter of time. He said this was our practice run. He was right. One month later we got another call. This time we were prepared with our bags packed and ready to go. My second match was from a 70-year-old, and it was a good kidney. I didn't let the past failure weigh me down. This was my chance. It was time for us all to celebrate!

### What is life like after transplant?

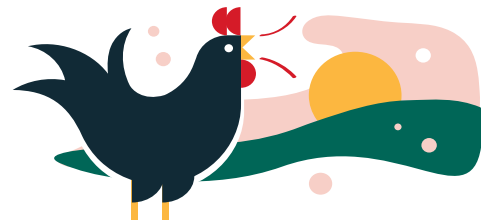
Today, I'm living without pain. Accepting the high-KDPI kidney gave me the chance to get a transplant within 4 months! My husband and I are back to being active, traveling, and living a life full of adventure. I just celebrated my one-year transplant anniversary and my 50th wedding anniversary. Now I'm looking forward to our first vacation after my surgery. I really have to thank my husband. I knew I wanted a transplant from the beginning and he supported me all the way through the process. He kept me motivated and I hope my story motivates others to stay strong and determined too.

“Keep looking forward to the good that lies ahead. You will get there.”



### Compare Transplant Centers

All transplant centers have different criteria and waitlist times. It's important to check and find the center where you meet all of the criteria. That is one of the fastest ways to get a kidney.



### Get Started Early

The sooner you get evaluated, the sooner you will hear from each transplant center as to whether you are eligible to receive a kidney from them.



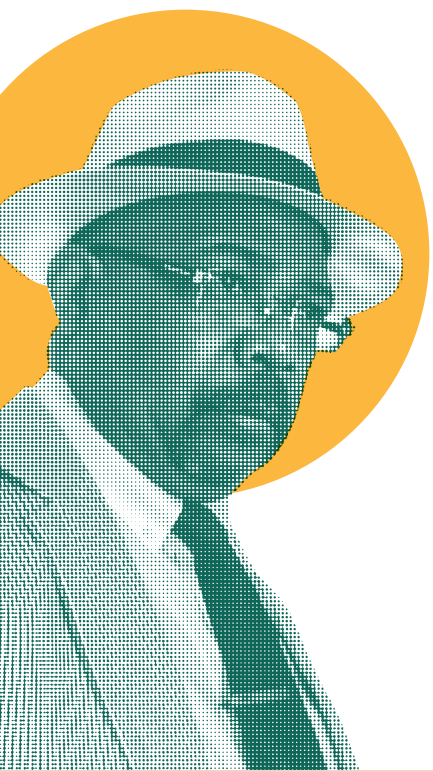
### Stay Positive

You have to keep a positive attitude about being on the waitlist. Sometimes you'll get an offer. Sometimes it doesn't work out. Don't worry—another kidney will come your way.



### Set Motivating Goals

I chose transplant from the start. My big motivator was taking my first vacation after surgery. Remind yourself of your post-transplant goals to keep you going.



**Bobby's Story**

# A Goal for Life

*I lived a reckless life before kidney disease. I had been a heavy drinker all my life. My kidney failure was a real wake-up call that things had to change. If I was going to win my life back, I had to fight for it.*

## **What was your journey to transplant like?**

It was a huge shock to find out my kidneys had failed. I kept passing out but just assumed it was because of the alcohol. Turns out, it was my kidneys trying to get my attention.

I knew to get on the transplant waitlist I had to stop drinking. Getting sober wasn't going to be easy, but I knew it would be worth it. Working to get on the list and stay active gave me something to fight for. I turned to my church community, Alcoholics Anonymous, and patient support groups for help. So many people started helping me. They brought me food, took me to appointments, and encouraged me to stay strong. My AA sponsor told me something I'll never forget: "Don't wait for your ship to come in—swim out to meet it." So, I made it happen. I got myself sober, got my transplant workup, and got on the list.

## **What was it like when you got your kidney offer?**

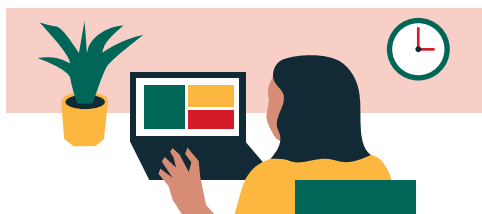
It was two or three years before I got my call. I was in church on Sunday, walking down the communion line, when my beeper went off. I got communion and then went and got my kidney. The people at church who supported me on my journey were right there when I got the call. It was one of the coolest moments of my life.

## **What is life like after transplant?**

To say it's great is a huge understatement. After my transplant, I met my donor's family. I now think of them as my own family. I'm an only child and have no kids, but through my donor, I now have three sisters, another mother, and three kids. We even spend Christmas together.

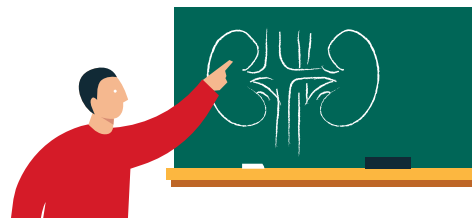
About six months after my transplant, I was asked to manage the Kidney House—a place that provides food and shelter for out-of-state transplant patients and their families while they receive their treatment. Twelve years later, I still manage it. I love working there—it's really been my home. I do just about everything I can for the ESRD community. People came together to support me when I had my transplant. Now I'm doing my best to pay that gift forward.

“Ask questions. Do research.  
No one can be a better  
advocate for you than YOU.”



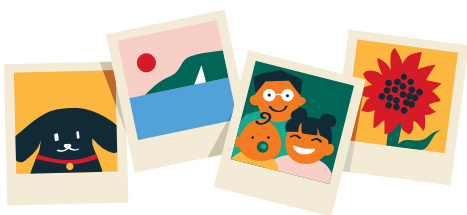
### Keep Working

If you only do dialysis, that's all you're going to think about. If you have a job, you have something else to focus on. Stay productive.



### Attend a Kidney Class

I teach a class about coping and dealing with dialysis. Find a class like mine and ask questions. Keep learning so when the day comes, you're prepared.



### Focus on Life, Not on Waiting

Don't concentrate on, "Why not today?" Your kidney offer will come. Just live your life, continue to take care of yourself, and make plans for the days to come after your transplant.



### Volunteer to Help Others

The kidney community is very tight knit. I visit dialysis centers to give patients hope. Sharing your steps to kidney transplant can help someone else stick to the journey too.





Austin's Story

# Two Transplants. Twice as Grateful.

*I was born with two nonfunctioning kidneys. When I was four, my mom gave me one of hers. Growing up, I didn't know how to talk to my friends about my transplant. When you're a kid, anything that makes you different is embarrassing. I was embarrassed for a long time, but now I'm proud to share my story.*

## **What was life like before dialysis?**

I hated feeling different from the other kids. I was afraid they would think I was weird because of my transplant. The kidney that I'd had for 14 years was still healthy, and so was I. But sometimes, particularly after the loss of my grandfather, and during other times of stress, I would forget to take my meds. I had no idea the impact that it would have on my kidneys. Four months before graduating high school, I went into kidney failure for the second time.

## **How did you cope with waiting for a transplant?**

It was really hard to have to go on dialysis as a teenager when my kidney failed. I was depressed. My face was puffy, and I looked so drained. I didn't even recognize myself. All my friends were graduating but I was stuck in a dialysis chair. Luckily, my older brother helped me keep my head up and got me through it.

I knew what another transplant could mean for my freedom – it would give me my life back. To stay motivated until I got a kidney match, I listened to patients' stories at transplant events and on YouTube. I Googled everything I could find to make sure I was ready when I got the call. Whenever I got discouraged, I wrote down each obstacle I was facing and found a way to share how I was feeling. While I did miss a lot of moments in high school, I tried to find other ways of living the life of a typical teenager. Instead of my high school's senior prom, I went to a renal community prom instead. It was a blast!

## **What is life like after transplant?**

It's been eight years since my second kidney transplant. I'm able to live on my own, travel, go to college, get a job. Finally, I was like every other guy in his mid-twenties. Some things are still hard, but I learned from my transplant journey not to let anything get in the way of my dreams. Whenever I'm dealing with depression or mood swings, I play music, draw, or focus on goals. I just got my degree as a Child Life Specialist to help kids and their families deal with illness and disabilities. Today, I give back and motivate others the same way I was motivated. I reach out to kids going through kidney disease and share my story. I know what it's like at a young age to struggle with a life-threatening illness. It's hard, but with determination, you can get your freedom back.

“Take care of your kidneys and they will take care of you.”



### Take Charge of Your Health

When I first went on dialysis, I didn't know how to take care of myself properly, so I ended up back in the hospital. Now I ask all the questions I can. You should too.  
*It's your life.*



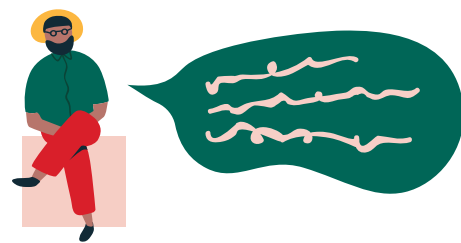
### Develop Creative Outlets

When you have tough times, use a creative activity such as writing, drawing, or playing music to relax and focus you back on your goals. You can even just write down what you're going through to get it all out.



### Attend Events Near You

I had to miss my high school prom because I was sick, but I was able to go to a renal prom with other teenage patients like me. There are lots of ESRD events and ways to join the community. You're not alone.



### Tell Your Story

Kidney disease is part of your story—like it is mine. Your unique experience will resonate and provide motivation to others with others with ESRD. Share your story to help someone else.