

Reaching the
Gold Standard ...

Fistula Journeys



My Lifeline

By Diana Headlee-Bell, a member of The Renal Network Board of Trustees and Network 4 Patient Advisory Committee

It's been thirty-six years since my diagnosis of Chronic Kidney Disease. Fourteen of those years were spent on hemodialysis. I started hemodialysis at the age of 15, under an emergency, to place me on hemodialysis immediately they had to place a shunt in my right ankle. The risk of infection was high, so I had to be careful with the site. It was cleaned and wrapped every time I had my hemodialysis treatment, three times a week. It was a couple of months after that I did receive my fistula.

A fistula is formed under the skin by sewing a vein to an artery. I followed every instruction I was given regarding my fistula. How it was important to keep the site clean, exercising it, not to lay on that arm and not to lift anything more than five pounds. For the next three years while on dialysis, I had learned to cannulate myself, it became easier for me to tolerate the cannulating when I had control.

On the third year I had received my second transplant. The kidney transplant was a success, so two years after receiving it, I asked for my fistula to be tied off. Over the years I have learned, that I should have not done that. My fistula is a lifeline. Transplants are not a cure, it is an option. Fortunately, I did have that kidney transplant for eighteen years. I lost the kidney due to treatment for pneumonia. While in the hospital, I knew I was losing the kidney because

of the effects of the toxins building up in my body. I was losing tremendous amount of body weight, and had a very hard time walking. My nephrologist then discussed with me the treatment options for starting me on dialysis. The treatment options we discussed at this time were unheard of 18 years before. She reviewed peritoneal dialysis and home-hemodialysis and in-center hemodialysis. She gave me the day to think about it. I was so happy that there were other options. I just had to pick one. The following day, she came back asking what option I had chosen. It was at that moment I burst into tears. She hugged me and kept telling me you can get another transplant, we will get you on the list right away. I looked at her and said that was not the reason why I was crying, I couldn't decide if I wanted peritoneal dialysis or the hemodialysis. It was finally decided that I would not make a good candidate for peritoneal dialysis. Hemodialysis would become my option.

It was important that I would get dialysis right away. I was sent off to surgery, they placed a central venous catheter in my chest, and also



Pictured above: Diana Headlee-Bell

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placed a fistula in my upper left arm. The fistula had to have time to mature, so the catheter was used in the mean time.

I was told the risks involved having the catheter. A catheter puts me at risk for serious blood infections, they can clot easily, and they may need to be changed often. Also putting me at risk for bad clearances, due to this, my hemodialysis time would have to be increased. Instructions were given to watch for the signs of infection, such as fever, pain at the site. I was also not able to shower, I had to take baths. It finally came time that my fistula had matured. They were able to cannulate it successfully. After a few treatment's, I was scheduled to have my catheter removed surgically. I was happy to get back to my showers.

I was able to use the fistula for approximately one year. I had developed pseudoaneurysms on the fistula. At that time, I also had been in training for home nocturnal hemodialysis, when my nephrologist noticed them. She had told me she did not want me to go home to do dialysis until my fistula had been taken care of surgically. During surgery, my surgeon decided it was best for me to have a graft placed in the same area. It was an AV bridge graft. Grafts require more care than a fistula. A graft is created under the skin by connecting an artery and a vein with a foreign synthetic vein. With my graft I had to have

frequent fistulagrams to open up stenosis, also known as an abnormal narrowing in my blood vessel. The narrowing was always located in my upper left chest just above the graft.

I did have my graft for three years. They don't always last. I had the unfortunate experience of my graft bursting. Thankful I was in a hospital setting. The following morning I went into surgery for repair of the access. The surgeon again placed an AV bridge graft and placed a central venous catheter for immediate use.

I had stated at the beginning of my story, that I had my first fistula tied off and should have not had that done. If I had kept that access, I would have not had to have the surgeries for another access to return to hemodialysis. The transplant was not a cure. It

is just an option. Fistulas can work for many years and sometimes decades. The golden standard for hemodialysis access is the fistula. I would recommend talking to your surgeon to find out whether you can qualify for one. For the last eleven years I have been on in-center nocturnal hemodialysis and awaiting my third transplant.

Vascular Access is a Hemodialysis Patient's Lifeline.

Five reasons to consider an A-V Fistula:

1. Fewer infections
2. Fewer hospitalizations
3. Fewer problems with clotting
4. Better blood flow for better treatment
5. Usually lasts years, compared to weeks or months for other access types

Discuss with your doctor and healthcare team your preference for an A-V Fistula.



The Patient Leadership Committee, guiding The Renal Network, Inc. education efforts, wanted to support the Fistula First Breakthrough Initiative through the words and experiences of other patients.