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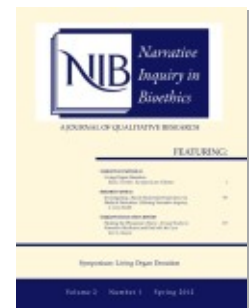
## Lessons Learned: The Realities of Living Organ Donation

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our whole family spent together. I often still struggle with feelings of anger and shame over my emotions.

I have returned back to my normal life at home. Working, furthering my education, planning my wedding and living my life. Dad has returned to his, and life did not change. I am not the princess daughter or held on some pedestal by my father. That is perfect for me; I don't want to be remembered as a hero, I want to be remembered as someone who spread the word about live organ donation. I am sure the process of live organ donation improves with each donation. The people I have encountered during our journey have forever touched and inspired me to be a healthier and better person. I want people to know live donation is an option, and even though I experienced life-threatening setbacks and complications, I would make the same decision 100 times over again.



### **Lessons Learned: The Realities of Living Organ Donation**

Donna L. Luebke

All I really needed to know I learned after my donation . . . years later . . . still learning . . .

The image remains in my mind as if it were yesterday. She was sitting on the edge of the bed, looking out the window. It was in May, 1994. The transplant coordinator had just told me that I was a perfect, six antigen match for a close relative. I knew I would be a match because we looked nothing alike.

I walked into the room, sat on the bed, and gave her the news from the transplant center. "It will be okay" I whispered. Then, I held her in my arms and we both cried for what seemed like hours.

Our family did not know she had kidney problems until a month earlier. She was seeing a kidney specialist at the hospital where she worked as a nurse. But, life for her changed drastically once she was admitted to the hospital, a catheter placed,

and dialysis started. She was then referred to the kidney transplant program for evaluation. The Chief of Nephrology told her he would not list her for a deceased donor kidney until all family members were tested. Could he have been any more coercive or threatening? Had I been there, I would have slapped him. They would not get my family. I would not let anyone else donate. No one was going to cut my family open for a kidney. We would leave the wait list for other candidates. I checked the national list. 20,000 were waiting for a kidney transplant.

### **Preparing for Surgery**

From May to the day of surgery, time moved fast. I worked as Trauma Coordinator for a level I trauma center. In June, I transitioned to work in the Surgical ICU as a staff nurse. In September, I was planning to start a nurse practitioner program.

As I write my story, memories flood back—memories I would rather forget. I, too, met with the Chief of Nephrology. He sat behind his desk—distant and stiff. He asked what I knew about being a kidney donor and what having one kidney would mean. I told him I had read an article which stated I could get high blood pressure or have protein in my urine. He nodded his head and said "Okay", offering nothing more.

Next, I met with the transplant social worker. Then it was test after test, to histories and physicals, and finally, to a visit with the Chief of Urology. He explained that he would need to remove a rib to get to my left kidney. I was more upset about losing a rib. It was enough for me to lose a kidney.

In order to prepare for this major surgery, I took leave from my job. My life, health, and disability insurance were up to date. I asked my primary care physician for his thoughts about my donating. If he had any reservations, the surgery would not have taken place. I had social supports from family, friends, nursing colleagues and physicians at my own hospital. In my own way, I put together an "Independent Donor Advocate Team" long before the term was popular. My advisors and support system were truly independent of the transplant center and my well-being was their only concern.

I had a will and a document with a designated health care power of attorney. I had an advanced directive to be a deceased organ donor if there was an adverse event in the Operating Room. My relative, the intended recipient, would get a kidney. Others would get the rest of me. Our pastor gave us the Sacrament of the Sick at a Mass with a community of support. On the Friday before surgery, we had a cookout with family and friends. We were ready.

### The Surgery

The surgery took place as scheduled in 1994. My relative was admitted the day before surgery and prepared for the transplantation of my kidney. I went in the morning of surgery with my family. In the predawn dark, it was a long 40 mile drive with little conversation. I felt numb inside. No time for emotions or second thoughts.

I spent six days in the hospital. The surgery hit me like a ton of bricks. I had an anesthesia reaction with nausea and dry heaves for three days. The epidural for pain control was great for the first few days, but none of the oral medications relieved the pain. I alternated them every four hours with Tylenol and hoped that with each day, I would have less pain.

Prior to surgery, I walked three miles per day. Now, I was exhausted just taking a shower. Once home, I found I could not even walk a block. Stairs were even more difficult. I was short of breath and easily fatigued. Each day I would take one more step. I tried to be strong for my kidney recipient. Within 10 days of surgery, I dragged myself to the start of my nurse practitioner classes.

I returned to the transplant center for follow-up only once. My dressing was removed. The incision looked fine. No one asked about my psychosocial well-being. Any subsequent care would be per my physicians. A letter was sent to my physician with instructions to check my kidney function on an annual basis. From my blood work confirming the six antigen match to the postoperative visit—my entire interaction with the kidney transplant program was over within four months.

### The Nightmare of a Failed Graft

The next part of our story is not easy to put into words. It is almost too painful; a story that includes betrayal and horror. We never had that happy ending. My kidney was supposed to make the recipient better. Instead, my family and I watched as she sickened and almost died. Her underlying kidney disease had been misdiagnosed. Within a year of donation, my kidney started to fail in the recipient. Within 18 months, she was back on dialysis. I asked her surgeon to figure out why since I only had one to give. The answer never came from the transplant doctors.

I was the health care professional who figured out what was wrong with her—much later, when she was near death. Once I gave her doctors the correct diagnosis, it took a deceased donor liver transplant to save her life at a second transplant center—and later, another kidney transplant. As transplant patients and live donors, we are informed that a transplanted kidney will not last forever and medical errors happen. However, my relative's physicians layered one oversight on top of another. Their cavalier attitude and negligence led to an emergency hospital admission for her, the loss of a perfect six antigen match kidney—and incidentally put my life at risk from a surgery I did not need to have for my own health. None of these lapses can be explained away as medical 'mistakes.' My kidney should have been that 20 year plus graft survival organ. Worse yet, not one physician at the initial transplant center owned up to his or her part in the failure to correctly diagnose and treat the disease which almost killed my relative.

### My Life Since Donation

I believe each step we take in life prepares us for where we go next. Prior to 2003, I never identified myself as a living donor. I assumed this role when the Executive Director of our local Organ Procurement Organization told me the United Network for Organ Sharing (UNOS) was looking for living donors for its Board of Directors. She nominated me. From 2003–2006, I served a term on the Board

of both UNOS and the Organ Procurement and Transplantation Network (OPTN). Since 2003, the focus of my life has been my experience as a living kidney donor. Since 2003, I learned that my experience was not unique as I have met others with stories to share.

Recently, I read my donor surgery operative report. It stated, “reconstruction of the diaphragm was done with . . .” I did not consent to “deconstruction” of my diaphragm. After surgery, I developed a pneumothorax. Neither my primary care physician (PCP) nor I were told there was a 10% risk of developing a pneumothorax or collapsed lung with open nephrectomy—and we were not told afterwards. Worse yet, no one at the transplant center listened to my lungs or ordered a repeat chest x-ray to be sure the pneumothorax had resolved. There is so much more I know today regarding living organ donation than I did in 1994. I learned that I am more than a live organ donor. I am a person whose life matters just as much as the intended candidate. I learned that the donor surgery is only one day in all my days on this journey of living donation. I learned I was not fully informed of the risks; not fully informed of what was being done to me in the operating room; not fully informed or educated about how to take care of my health and my lone kidney after surgery. I was not offered mental health or social supports pre- or post-donation. Although I was told to avoid non-steroidal medications like Motrin and contact sports, I was not told about the risks posed by IV contrast dyes, other medications I might need in the future, or from diseases like hypertension and diabetes. I was not told about the increased risk of cardiovascular morbidity and mortality associated with reduced kidney mass or a reduced glomerular filtration rate (GFR).

If I could go back in time, what would I have done differently? I would have investigated the education, training, and experience of the medical physicians and surgeons at the transplant program who took care of my relative and me. I would ask for outcome data on recipients and live donors. I would have obtained copies of all the forms I signed. I would have obtained copies of all my diagnostic tests. I would have obtained, in writing, the

terms of insurance coverage for my donor surgery, any complications, and subsequent care needs. I would have asked more questions and demanded more answers.

Would my decision to donate have been any different? No easy answer when looking back all these years later. Do I have any regrets? I would never regret helping someone I love. I do regret my “blind trust” of the surgeons and the transplant center staff. None are excused for the lack of informed consent or lack of attention to my care needs including my mental, physical, emotional or spiritual well-being. Do I feel better about myself or have an “enhanced sense of well-being?” I did not need to be cut in half to feel good about myself—rephrase the question.

The decision to donate is based on trust; trust in a system that is supposed to care about patients—including live donors. Honest, accurate, and complete risk disclosure is important to all of us. We are much more than a kidney or piece of liver. My relative was much more than just a kidney transplant.

All I really needed to know I should have learned in 1994 . . . not years later . . . still learning. . . .



## Sarah's List Exchange Experience

Sarah A. McDaniel

### Part I—Family Dynamics & Informed Consent

I was immediately drawn to the paired kidney exchange program as a way to help my mother avoid dialysis and survive her chronic kidney disease (“CKD”). The concept of helping two patients with the act of donating one kidney greatly appealed to me. “Why *not* do it?” was my attitude.

When I first described the paired exchange program to my mother, she dismissed it. She had been