



# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Receiving the Gift of Life:  
Stories from Organ Transplant Recipients





# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

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### **Special Thanks to**

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## Introduction

# Receiving the Gift of Life: Stories from Organ Transplant Recipients

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**Conflicts of Interest.** The authors report no conflicts of interest.

**Abstract.** This symposium includes thirteen personal narratives from people who have received at least one organ transplant from a living or deceased donor. These narratives foster better understanding of the experiences of life-saving organ recipients and their families, including post-transplant difficulties experienced—sometimes requiring multiple transplants. This issue also includes three commentaries by Macey L. Levan, Heather Lannon, and Vidya Fleetwood, Roslyn B. Mannon & Krista L. Lentine. Dr. Levan is a living kidney donor and associate professor of surgery and population health. She writes and teaches on organ transplant and has expertise and experience in governance at the federal level as a member of the board of directors for the U.S. Organ Procurement and Transplantation Network. Dr. Lannon is a social worker and transplant advocate. Her work and interest in the topic were inspired by her husband who needed a heart transplant. Dr. Fleetwood is a surgeon specializing in liver transplantation, pancreas transplantation, kidney transplantation, as well as living donor nephrectomy. Dr. Mannon is a nephrologist and professor of medicine, pathology and microbiology. Her work focuses on understanding and improving long-term kidney transplant outcomes for patients, donors, and caregivers. Dr. Lentine is a nephrologist specializing in treatment of adult patients with kidney disease. She is a researcher and co-chaired the international work group that developed guidelines for living donor kidney transplantation.

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**Key Words.** Medical ethics, Organ transplant, Narratives, Physician-patient relations, Decision making, Gift of life, Organ recipients, Living donation, Living donors, Deceased donation, Deceased donors

## Introduction

Organ transplantation lies at the intersection of clinical ethics, oriented around the care of individual patients, and

public health ethics, which shifts the moral focus to the needs of the wider community, yielding both technical and ethical complexities. Bioethical scholarship has largely focused on the donor

side of organ transplantation, with issues such as the dead donor rule and the determination of death, physicians' obligations to donors and pre-death interventions designed to benefit recipients, and strategies for increasing the pool of donated organs. On the organ recipient side, there are no fewer ethical dilemmas involving the interplay of medicine, law, public policy, the social determinants of health, and institutional practices (Caplan & Coelho, 1990; Caplan, McCartney, & Reid, 2015; Veatch & Ross, 2015). Here, we will highlight just some of the ethical concerns involving organ recipients.

Organ transplantation professionals are charged with navigating the organ transplantation system with maximal *efficiency* while also ensuring that access to organ transplantation is *equitable* (Organ Procurement and Transplantation Network, 2022). Given the scarcity of donated organs, quality metrics such as graft success, limiting adverse outcomes, and recipient survival are assessed throughout the transplantation process, resulting in the selection of recipients well-suited to meet these goals (Gordon, 2000). This challenges equitable access as social determinants of health contribute to higher levels of comorbidities among marginalized groups that often render someone *not* medically suited for transplantation (Jesse et al., 2019; Keddis et al., 2018; Mazumder et al., 2021; Wall et al., 2020).

Once transplanted, many recipients will have complex health and practical support needs such as mediation sorting, watching for signs of infection or rejection, as well as help with bathing, cooking, and wound care, among others. Throughout the transplant journey, recipients will need social and emotional support, both from their transplant team and loved ones. Many transplant centers help patients plan for who will care for them and then evaluate this care plan as part of the psychosocial criteria investigated prior to listing decisions (Berry et al., 2019). Organ recipients are thereby plunged into the contemporary technologic paradigm of biomedicine, transforming their whole lives—and those of their families and friends—to conform to the directives of their transplant team. Responsibility for the transplant center's metrics achievements

is passed along to recipients and caretakers (Heinemann, 2016).

Public narratives of organ transplantation usually show recipients as fully-recovered with no limitations to their lives or lingering health issues, often including expressions of gratitude. Organ transplantation is thus seen as a miraculous rebirth back into health without frailty. The public does not see the challenging road that leads up to transplantation, the permanent immunocompromised state, acute or long-term graft failures, people who regret being transplanted, or those who, for whatever reason, do not adhere to their post-transplant care plan (Tang et al., 2021). Most people are unaware that, even after transplantation, health management is still challenging, and sometimes comes with lingering chronic conditions. The purpose of this issue is to learn from the stories of organ recipients in order to tease apart various moral assumptions, gaps, wrongs, insights, and experiences. The stories attend to the details of networks of care, the interplay between donor families and organ recipients, the arduous journey to transplantation (and sometimes re-transplantation), and conflicts of medical and personal values. They also highlight themes of resilience, technology, gift-giving and receiving, sense of self, and moral responsibility.

## The Call for Stories

The 13 stories included in this issue detail a variety of positive and negative experiences with receiving an organ transplant from a living or deceased donor. We received many stories in response to our call and have included five additional stories in the online supplement for this issue.

In the call for stories we sought personal narratives from organ recipients who had firsthand experience with the ups and downs faced from diagnosis through post-transplant life. Furthermore, we wanted to understand differences in experiences and decision-making about receiving organs from living versus deceased donors.

We were also interested in learning about how receiving an organ transplant changes recipients' quality of life and outlook on life. We encouraged authors to give readers an idea about the

complexities of decisions they had to make, including weighing risks and benefits. We also aimed to learn about the support and advocacy recipients needed to navigate the transplantation process.

Authors were asked to consider the following questions:

- Why did you need an organ transplant? What solid organ(s) did you receive?
- Was your donor living or deceased? How did that affect your experience?
- What has been positive about receiving a transplanted organ?
- What has been challenging about receiving a transplanted organ?
- Was anything in your overall experience particularly surprising?
- Was there anything you wish you had known before you received a transplanted organ?
- What lessons would you want to share with transplant professionals?
- What would you like to share with individuals who are currently awaiting transplantation or who have recently received a transplanted organ?

The editors of *Narrative Inquiry in Bioethics* published the call for stories in the *NIB* newsletter and on the *NIB* Website. Additionally, the call was posted on several social media platforms including LinkedIn, Facebook, and Twitter. It was distributed through the American Society for Bioethics (ASBH), the Association of Bioethics Program Directors (ABPD), the Association for Practical and Professional Ethics (APPE), the Medical College of Wisconsin (MCW), and the University of North Carolina (UNC) Center for Health Equity Research listservs. The UCSF Lung Transplant Program, Donor Connect, and the Pediatric Transplant Center at Lucile Packard Children's Hospital Stanford also helped us distribute the call along with many colleagues and friends.

Many authors expressed gratitude in being able to share their stories with the hope that their story can raise awareness while also reassuring and inspiring others. Despite the magnitude and nature of obstacles recipients had to overcome, many authors expressed that they would go through the experience again. Collectively, these stories demonstrate a broad scope of struggles and victories inherent to receiving an organ transplant.

## The Narratives

The authors include 12 organ recipients and the mother of a recipient, all of whom have firsthand experience with the transplantation process and the turbulent, complex journey it entails. Authors received their transplants during a range of life stages and ages. Collectively, authors received a variety of organs (e.g., heart, kidney, liver) from a combination of living and deceased donors. A few authors needed multiple organ transplants throughout the course of their care. Some had a family history of disease that foreshadowed their own medical hurdles, often taking years or decades to fully unfold. Others had an abrupt foray into transplantation with unexpected declines in organ function that required immediate action.

Narratives provide unique insight into the lives and experiences of authors before, during, and after transplantation. The stories they share reflect the often intense emotional journey that accompanies arduous physical experiences of recipients. Their bodies change. Their relationships with friends and family change. Their priorities and outlooks on life change. Authors share the joys, anxieties, grievances, and lessons learned from their encounters with the transplant process. Stories highlight the magnitude of trust recipients must put in others, the overwhelming sense of gratitude toward donors and their families, the criticality of a quality support system, and the need to self-advocate. Taken together, authors share their stories in hopes of cultivating a deeper, more humanistic understanding of the transplant process by those who read their stories.

## The Commentaries

This symposium includes three commentaries. The commentaries draw out themes and lessons learned from the narratives. These commentary authors include experts in nephrology, living and deceased donor transplant, bioethics, health law and policy, and patient advocacy.

Macey L. Levan is an Associate Professor of Surgery and Population Health and the Director of the Center for Surgical and Transplant Applied Research Qualitative Core at New York University.



She is a living kidney donor and a former member of the board of directors for the U.S. Organ Procurement and Transplantation Network.

Heather Lannon is a social worker and transplant advocate. Dr. Lannon's dissertation focused on heart patients and their caregivers who had to relocate to access heart transplants. Her research was inspired by her personal experience of relocating from Newfoundland to Toronto with her husband, Jamie, who needed a heart transplant. She previously worked as the Living Donation Outreach Coordinator at the Ajmera Transplant Centre at Toronto General Hospital.

Vidya Fleetwood is an Assistant Professor of Transplant and Hepatobiliary Surgery at Saint Louis University. She became interested in transplantation when a close family friend underwent a life-changing kidney transplant. Twenty years later, her friend is still thriving. Dr. Fleetwood now specializes in liver, pancreas, and kidney transplantation as well as living donor nephrectomy.

Roslyn B. Mannon is a Professor of Medicine, and Pathology and Microbiology at the University of Nebraska Medical Center in the division of nephrology. She is a past president of the American Society of Transplantation and current chair of the Women in Transplantation Initiative, co-chair of the Scientific Registry of Transplant Recipients, and chair of the American Society of Nephrology Policy and Advocacy Committee. Dr. Mannon's career in transplant nephrology has focused on understanding and improving long-term kidney transplant outcomes for patients, donors, and caregivers through her societal activities.

Krista L. Lentine is Professor of Medicine/Associate Director of Nephrology, Medical Director of Living Donation, and the Jane A. Beckman/Mid-America Transplant Endowed Chair in Transplantation at Saint Louis University. She is senior staff of the Scientific Registry of Transplant Recipients (SRTR), chair of the American Society of Transplantation (AST) Living Donor Community of Practice, a past chair of the Organ Procurement and Transplantation Network (OPTN) Living Donor Committee, and first author of the Kidney Disease: Improving Global Outcomes (KDIGO) Living Donor Guidelines.

## Conclusion

As a whole, this symposium helps cultivate a more robust, intimate understanding of the experiences and perspectives of organ recipients and their families than has historically been explored. Their stories can help transplantation professionals and the public better comprehend the complex needs of organ recipients and their families at all stages of the organ transplantation cycle, including needs related to receiving social and emotional support, maintaining quality of life, and adjusting to substantial fluctuations in physical health. The authors' stories are complemented and enhanced by expert commentaries that provide a compelling synthesis of these experiences. In many cases, the expert commentators have a personal connection to organ transplantation, which makes the commentaries uniquely insightful. In sum, the stories and commentaries in this symposium present a valuable opportunity to learn from those with firsthand experience of receiving an organ transplant and identify ways that the transplantation experience—from first being listed to lifelong after-care—can be improved for others moving forward.

## References

- Berry, K., Daniels, N., & Ladin, K. (2019). Should lack of social support prevent access to organ transplantation? *The American Journal of Bioethics*, 19, 13-24. <https://doi.org/10.1080/15265161.2019.1665728>
- Caplan, A. L., & Coelho, D. H. (Eds.). (1999). *The ethics of organ transplants: The current debate*. Prometheus.
- Caplan, A. L., McCartney, J. J., & Reid, D. P. (Eds.). (2015). *The ethics of procuring and replacing organs in humans*. Georgetown University Press.
- Gordon, E. J. (2000). Preventing waste: A ritual analysis of candidate selection for kidney transplantation. *Anthropology & Medicine*, 7(3), 351-372. <https://doi.org/10.1080/713650608>
- Heinemann, L. L. (2016). *Transplanting care: Shifting commitments in health and care in the United States*. Rutgers University Press.
- Jesse, M. T., Abouljoud, M., Goldstein, E. D., Rebhan, N., Ho, C.-X., Macaulay, T., Bebanic, M., Shkokani, L., Moonka, D., & Yoshida, A. (2019). Racial disparities in patient selection for liver transplantation: An ongoing challenge. *Clinical Transplantation*, 33(11), e13714. <https://doi.org/https://doi.org/10.1111/ctr.13714>
- Keddis, M. T., Sharma, A., Ilyas, M., Zhang, N., Khamash, H., Leischow, S. J., & Heilman, R. L. (2018). Transplant

- center assessment of the inequity in the kidney transplant process and outcomes for the Indigenous American patients. *PLOS One*, 13(11), 1-16. <https://doi.org/https://doi.org/10.1371/journal.pone.0207819>
- Mazumder, N. R., Simpson, D., Atiemo, K., Jackson, K., Zhao, L., Daud, A., Kho, A., Gabra, L. G., Caicedo, J. C., Levitsky, J., & Ladner, D. P. (2021). Black patients with cirrhosis have higher mortality and lower transplant rates: Results from a metropolitan cohort study. *Hepatology*, 74(2), 926-936. <https://doi.org/https://doi.org/10.1002/hep.31742>
- Organ Procurement and Transplantation Network. (2022). Equity in access to transplant. Retrieved August 3, from <https://insights.unos.org/equity-in-access/>
- Tang, J., Kerklaan, J., Wong, G., Howell, M., Scholes-Robertson, N., Guha, C., Kelly, A., & Tong, A. (2021). Perspectives of solid organ transplant recipients on medicine-taking: Systematic review of qualitative studies. *American Journal of Transplantation*, 21(10), 3369-3387. <https://doi.org/https://doi.org/10.1111/ajt.16613>
- Veatch, R. M., & Ross, L. F. (2015). *Transplantation ethics* (2 ed.). Georgetown University Press.
- Wall, A., Lee, G. H., Maldonado, J., & Magnus, D. (2020). Genetic disease and intellectual disability as contraindications to transplant listing in the United States: A survey of heart, kidney, liver, and lung transplant programs. *Pediatric Transplantation*, 24(7), e13837. <https://doi.org/https://doi.org/10.1111/ptr.13837>

## Personal Narratives

### Receiving the Gift of Life: My Kidney Transplant Story

Judith W. Ryan

**A**s one of three siblings who all inherited an unfortunate gene from our mother, I was born with polycystic kidney disease (PKD). None of us knew of this, however, until later middle age, and my mother not until she was 76. I was the last sibling diagnosed at the age of 56. My brothers had been diagnosed some years before and jokingly started to look at me as a universal donor. Since I had a 50-50 chance of having PKD and with a mother who was one of eight children with none

of her siblings known to have the disease, I had not felt an urgency to be tested. Besides, I had no signs or symptoms. But now there was a reason. I made an appointment for a renal ultrasound and while having the procedure, I tipped the screen so that I could see the results. Although the technician was not happy with this, I was repaid with the view of my kidneys looking full of bubbles. Yes, our family was three for three in the genetic game of roulette.

I knew immediately how I was going to navigate this health issue. As an adult nurse practitioner I had a very good understanding of what was to come. I knew my blood type "O" was the most common and would mean the longest wait for a deceased donor transplant, at least five years if I were lucky and only after enduring several years of progressing renal failure. In addition, I had cared for dialysis patients and watched my mother endure with difficulty both peritoneal and hemodialysis prior to her death a year before my diagnosis. Knowing I would *not* choose dialysis left me hoping for a miracle of a living donor or, more realistically, managing my disease as best I could until I died.

The next step was managing PKD symptoms and issues as my kidneys continued to fail. One of the errors in my thinking during this time turned out to be that because I had two brothers who had the same disease and were ahead of me in their disease progression, I could follow their lead. It turned out that we manifested our disease very differently. My younger brother, who was diagnosed first, had to deal with significant pain from persistent cyst ruptures, monthly, biweekly then weekly. This continued even after his transplant until he had his native kidneys removed. The other two of us did not have to deal with cyst ruptures. Additionally, anemia was no problem for my younger brother but was for us older siblings. Significant fatigue and weariness were a problem for both of my brothers but not for me.

And so it went, as we compared our blood test results, that the idea of a living donor entered the conversation. I knew this would be a problem for me because how do you ask people to consider being a donor? I had difficulty asking friends for a ride to the airport. This is where the grace and kindness of others and divine intervention enter



our story—word about our medical dilemma spread through the visibility of my younger brother, a minister in New England.

Fortunately for me, my much beloved younger brother had dozens of people who wanted to be his donor. About 12 of these potential donors were actually tested before finding a match. One of his unmatched donors became the donor for my older brother (our first family transplant). Two years later, my other brother received his transplant. Three years later, after being told he was not a good match for my brother, this dear man came forward to be a possible donor for me. Hence, I got my transplant from an unused donor from my younger brother's group. Overall, we had living donors from three different churches located within an hour of each other in New England. I even lucked out and acquired the minister of one of the churches as my donor. All three of us received kidneys over five years from living donors who did not know my older brother or me, but they did know my younger brother and were all people of faith.

My actual kidney recipient experience, after meeting the transplant eligibility criteria, began with a phone call that I never expected to receive. Even though my two brothers had already received kidneys from two amazing women, I was more pessimistic and did not believe there would be a donor for me. The call was from a man who introduced himself and stated his interest in being my donor. He lived in my hometown in a state I left after college many years earlier. Next, we needed to meet. This was going to be worse than a blind date. It was going to be a very nerve-racking and intimidating interaction for me. How could I impress this potential donor that I was worthy of his taking this risk to give me his gift of a kidney? In addition, I was somewhat suspicious about his motivation as to why he would do this for a stranger. Apparently, his interest in being a donor for my brother was not person-specific (thank goodness). In addition, he said that by giving me a kidney, he could cure me. This was true, and surprisingly I had not thought of that. My kidneys had not been damaged by diabetes or hypertension, as is true for so many others needing transplants, and therefore, his gift

would not be compromised, over time, by these common diseases. He could indeed *cure* me. We passed the scrutiny of each other and my very successful transplant occurred eleven years ago with no episodes of potential rejection of the kidney during all this time.

As a post-transplant patient, there were now new issues and problems with which to deal. Side effects of the anti-rejection drugs, specifically hand tremors from one drug and diarrhea from the other, had to be addressed. In addition, being profoundly immune-suppressed, especially in the beginning, meant learning how to stay safe in many ways, such as in social situations and in what foods to avoid. As it turns out, this orientation was a perfect prelude in dealing with Covid-19. I know I am highly vulnerable to becoming infected, so I wasted no time getting vaccinated and boosted x2. Unfortunately, I have no confidence that my immune suppressed system can mount any protection against the virus, and my ongoing cautious behavior reflects this.

One strong recommendation I have for all transplant patients is to spend time and energy finding the right health care providers to help them navigate the change in their lives and the health care system. One of my first post-transplant physicians assigned to me was an arrogant man who had little interest in answering or even listening to my questions and issues. We were not a good match. I found it very discouraging to deal with him. I knew the kind of clinician I needed: someone smart, who listened, answered my questions, found out the answers, and did not con me. In short, it had to be someone who was interested in collaborating with me in establishing my plan of care. Thankfully, I received a solid recommendation from the transplant social worker who, after listening to me, nodded in understanding and directed me to my current wonderful post-transplant physician.

All in all, the most overwhelming issue for me post-transplant was how to really thank my donor. It is a most amazing thing for one person to risk their life for a stranger intentionally. I spent a great deal of time with my brothers and social workers trying to navigate this. I am overwhelmed with gratefulness and thank God for creating this path for my

brothers and me. Early on after my transplant, I made a comment to my donor about taking care of *his* kidney. He stopped me short and explained that it was not his kidney but mine. He had given me my life, and I was responsible for it. I have concluded that my most important acts of thankfulness revolve around all of my daily behaviors that protect and preserve my kidney.

My transplant center had monthly or bi-monthly seminars for pre- and post-transplant patients that covered informational sessions and opportunities for us to discuss coping strategies. A frequently arising topic was being grateful and how to express this, especially to donor families. Since I had a living donor, this was not an issue for me, but I found it very interesting. The social workers had developed a mechanism to reach out to deceased donor families while maintaining anonymity, and writing a letter to tell them what their gift meant to recipients. Donor families rarely refuse these letters but so many of the recipients I met had never sent a letter and they felt guilty and embarrassed about this and discussed it quite openly. I heard them say they could not find the words to express themselves, or they were not skillful writers, or were afraid the family would not find them good enough to deserve the gift. Others thought they were not “fixed” enough because they still had ongoing medical issues or that they had waited too long to write. One man had received his transplant 20 years before and was still bothered that he never said thank you. I would encourage transplant professionals, especially nurses and social workers, to actively assist recipients in understanding that it is never too late to say thank you.

Overall, my transplant experience has been gloriously successful but finding the right tissue match is just the beginning. Finding the right clinical professionals who welcome their patients’ endless questions and answer with clarity, thoroughness, promptness, and patience is critical for maintaining an effective transplant and a successful self-management lifestyle.



## Gaining a Heart But Missing Myself

Leilani R. Graham

I gathered it in my hands as it fell from my hairbrush, too saturated to hold anymore. It felt as if I were inside a movie and waiting for someone to yell “Cut!” but no call came. It continued to fall, feather-like onto the ground, individual strands glinting in the light of the bathroom window. My hair, nearly all of it, was gone.

Between the time of my heart transplant and the moment my hair began to fall out, I arguably had suffered enough. Transplant brought four open-heart surgeries, ten days on ECMO, an intra-aortic balloon pump, delirium, necrotizing pneumonia, and so much muscular atrophy that I had to re-learn how to walk. CPR, broken ribs, and the scar of a tricuspid clip from a botched biopsy: it was not the miracle I was hoping for.

The internal trauma had certainly taken its toll. I no longer knew how I really felt, thanks to copious pain meds that altered my mind and body. Each limb was foreign as I re-acclimated to how one grabs hold of a cup, signs their name, touches their legs. Externally, I was a mess: covered in deep purple bruises across my torso from the diabetes treatments, dead skin pooling in unwashed pores, my ankles swollen and indiscernible from my legs. But lacking a good mirror (or the desire to find one), I still felt like “myself” during my forty-five day hospital stay. I could feel my cheekbones protruding from thinning skin, saw through unfocused eyes from the tempestuous blood sugars, and my hair sat in a rat’s nest atop my head; but I was still me.

Arriving home, I felt like a newborn being brought into the real world for the first time. I needed help with everything—showers, sitting up, putting on shoes, even going to the bathroom. At age twenty-four, I felt I had regressed to the point of no return as I relied on others to do the simplest tasks. In addition, I was quarantined inside for three months, due to the risk of obtaining a fungal infection from the outside. Caged, and alone in my body, I was a trapped and wounded tiger: angry, hurting, and scared.

When I had been prepared for transplant—and I use “prepared” loosely because the information packet I was handed was insulting at best—I knew to expect the scars. I had no issue with that, having been cut open at my throat and chest for previous surgeries. I knew to expect a 12-inch line from neck to navel: the most evident sign I would now carry that I was disabled.

What I did not expect were the bullet holes—the sealed entrances of thick chest tubes that now dotted my lower torso. I did not anticipate the bruises on my arms and groin from arterial pokes. I felt violated as if I had walked into some kind of abduction and was rolled out, beaten, bruised, and, worst, *touched*.

But it wasn’t the physical trauma that hurt the most. It was that no one seemed surprised.

Immediately after transplant, the team’s focus is purely on survival. Survive the 30 days post-surgery. Survive the year. Metrics, uncomfortably tied to transplant center success statistics, funding, and clout have little to do with the patients themselves. What did I care to *only* survive a year? I wanted years. I wanted decades. It felt I wanted more than anyone was willing to pay attention to.

The conversation was narrowed to high-risk issues: infection, rejection, or other life-threatening conditions. While this makes sense on a clinical level, what constitutes a major event for a clinician may not be of the same emotional value to the patient. In my case, I was less occupied by how the steroids were working and more obsessed with their side effects, such as how much weight I was rapidly gaining. I walked into the clinic one day with the beginnings of stretch marks and a week later had claw-like ripples down my sides. My mood swings were explosive and terrifying. I had never experienced such a desire for food and hatred of my body at the same time. But in the eyes of a scientist, I was not experiencing rejection. The ejection fraction was improving. So there was no pressing issue. Some even went so far as to say, “but at least they kept you alive,” as if I were ignorant of what exactly I had just been through.

This wasn’t to say I was dismissive of the high-risks to which I was susceptible. I was terrified of

rejection; of another surgery; of ending up back on ECMO. I took instructions seriously and never once strayed from my medical regimen. But I had lost that sense of self that I had maintained during the hospital stay. Each new side effect felt more pressing because, unlike whatever was happening to the new heart deep inside, it was visceral. In the mirror, I had cheeks fit to burst and bugging eyes as a result of Cushing’s Syndrome. I could not run my fingers through my thinning hair without weeping. I no longer recognized who I was.

This sense of self is crucial to hold on to during recovery from a transplant. It was one thing to feel apart from my body, to even feel out of sorts—it was another to see a different person entirely in the mirror. Medications wreak havoc. The regimen is complex and affronting, and the responsibility unparalleled. “You must take care of this organ,” they told me. “You must protect yourself; prevent infection; protect your gift.” But who was protecting “me”?

What I discovered through my dissociation is that one essential piece missing from organ transplant post-operative care is patient-centric goal setting.

When patients are being prepared to be discharged, it would behoove the patient, caregiver, and clinical team to set up goals that focus on the patient’s quality of life. Perhaps the newly diabetic patient does not have a preference for what they eat and simply wants to get off insulin as quickly as possible. Becoming severely type two diabetic was more of a shock for me than feeling someone else’s heartbeat inside my chest.

The patient with extreme mood swings may wish to see psychology more often to better titrate medication. Why are depression and anxiety accepted side effects of most anti-rejection meds? Have we considered it might be the life-changing shock of transplant that triggers mental health issues more so than the meds?

A patient with limited resources may be concerned about getting back to work as quickly as possible, even if they aren’t 100% “back” to a normal state of being. This is where social work, therapy, and transplant coordinators should lead, having

more high touch with the patient's everyday life than a cardiologist.

Goal setting should be realistic. For example, the patient losing her hair cannot arbitrarily set a goal of getting it back quickly. They can, however, work with dermatology or pharmacy to see which medications might be contributing to the issue. They could get a referral to oncological services to see about wig fittings. Or, perhaps with better preparation and teaching, they could be better informed about what might befall them ahead of time. It may not make the outcome any easier to live with, but it would allow room for some appropriate acceptance.

Above all, providers for the patient should prioritize empathy in the clinical setting. In the end, there may be nothing they can do for a specific issue. Sometimes what patients need is support and an action plan from the people they see as having such control over their lives.

The nature of my distress was finally realized in the clinic when a doctor stopped typing on the computer, put his hands in his lap, and turned in his chair to face me. "I'm sorry," he said. "I'm a man: losing hair is a concern. But I know especially for women, losing their hair can be extremely upsetting." Just a brief moment—an acquiesce, a break from the lab values and charting and endless discourse on the importance of eating right—for the first time, I felt seen as myself again, for who I was.



### **Managing the Transition from Patient-Centered Care to Protocol**

David Slakter

I learned that I would need a kidney transplant in the summer of 2015. This was not a complete surprise to me, as I had been subjected to a number of tests and invasive procedures to investigate nephritis since I was a child. I had heard similar stories of clinicians performing repeated tests on my father for similar reasons without any conclusions.

Following my recommendation for transplant and consultation with genomics specialists, the cause of my kidney failure was determined to be Alport syndrome. What made Alport syndrome so difficult to diagnose in my case was that the associated mutation is a rare, autosomal-dominant one that has only recently been associated with the condition.

After reviewing the data on survival rates for transitioning to dialysis versus a transplant, my family and I then considered the success rates for living versus cadaver donors, and the success rates at various transplant centers. The current data favor the long-term outcomes of transplant over dialysis and living over cadaver donors. Since we had decided to focus on searching for a live donor, my nephrologist recommended contacting Renewal, an organization that specializes in connecting those in need of a kidney transplant with live donors and providing support for donors to make the donation process less burdensome.

On Renewal's recommendation, my family and friends reached out across their social networks to search for potential donors. Many of those tested for compatibility were eliminated on basic matching criteria, others due to previously undiagnosed medical problems. Finally, the wife of a childhood friend came forward as an eligible donor and was also an incredibly close match on the antigens tested for kidney transplants.

Having a living donor who was also a friend made the transplant experience somewhat less intimidating than it might have been. It meant the transformation of an existing relationship with someone already close to me, with fewer open questions about what may have motivated them to be so generous than if the donor had been someone I did not know. It also meant our families could be together in the waiting room, and that we shared in each other's recoveries.

Life post-transplant has been a significant improvement from what it was like immediately beforehand. Before my transplant, I regularly weighed food and consulted nutrition charts to gauge how much potassium I was consuming. To prevent too much potassium from building up in my bloodstream, I had to take sodium polystyrene

regularly. As one might guess from the name, it tastes much like burnt Styrofoam, and I could only ingest it with copious amounts of fruit-flavored syrup (strawberry covered up the awful flavor the best). There are other potassium binders on the market now, so fewer people with kidney failure will likely need to engage in such gustatory experimentation.

I was also able to engage in more activities than what was possible even years before my transplant. I had long experienced difficulty with aerobic exercises, but assumed the reason was merely being out of shape. Though I have always walked regularly, even the one-mile walk from my office to my apartment had become a chore by the end. Within a few months after my transplant, I was riding a bicycle all over NYC, from Harlem to Brooklyn and back regularly, and hiking trails in nearby state parks. I began sessions with a personal trainer and attained a level of fitness I had not reached since I played soccer as a child.

The transition from personalized care to one more driven by protocol has been a surprising and challenging aspect of the transplant process. While my previous experience with medical treatment has been individual meetings with physicians, my post-transplant care is managed by a team of nephrologists and other specialists in transplant care. My initial transplant nephrologist was automatically assigned to me. Because the standard of care for transplant patients is often driven by protocol, my assigned nephrologist recommended a biopsy on my transplanted kidney due to results in my recent lab tests. When pressed on the necessity of a biopsy in my case versus the potential risk, the nephrologist interpreted my questioning as a doubt of their expertise and ultimately ended our relationship.

This relates to a larger concern I have with transplant professionals, as I have encountered similar attitudes among some other doctors working with transplant patients. Some professionals can be dismissive of fears people may have about having additional procedures performed on them without a clear benefit. I understand that cutting and inserting objects into human bodies is a normal practice for those working in transplant medicine, but it is important to understand that it is not normal for

patients. Minimizing their concerns because the known potential negative outcomes occur only a small percentage of those times, when one of those outcomes is loss of the transplanted kidney, harms the patient trust necessary to maintain a high standard of care for transplanted organs. On the one hand, this concern of mine likely is due to my own family history of having invasive and painful procedures performed to no ultimate benefit. On the other, it is not unreasonable to expect medical professionals to be able to clearly explain the expected benefits and potential risks of a procedure they wish to have performed.

Once the nephrologist assigned to me no longer wished to see me, I had the opportunity to choose another doctor on staff whose bedside manner better suited my needs and who was willing to hear out my concerns and provide answers to my questions. My advice to other transplant patients is to take charge of their own care, or enlist the help of someone with the knowledge, connections, or force of personality to do so. Transplant staff have multiple patients, and it's easy for seemingly minor concerns to go unaddressed. There remain many unknowns in transplant medicine. It is important to have a transplant specialist who is not only knowledgeable but can also clearly communicate their knowledge and assessments to their patients. If your transplant nephrologist has been assigned to you randomly and you do not find them to be a good fit, do not be afraid to inquire about consulting with another member of the medical staff.



## **Ethical Issues Faced by a Kidney Transplant Recipient**

Elizabeth Crais

**M**y first kidney transplant occurred in 2004 with my research colleague, Linda Watson, as my donor. I had been living with Polycystic Kidney Disease (PKD) since being diagnosed in 1986. PKD is a hereditary disease



resulting in cysts growing in the kidneys and eventually taking over their function, leading to either dialysis or transplant. At the time of my diagnosis, I did not know my mother had the same disease until I called her that night to tell her of my new diagnosis. With her depression era attitude of “don’t talk about medical issues,” she had chosen not to mention it to any of the family. Mostly, she said not to worry about it, as she had it and was currently in her early 70s and other than high blood pressure had not had any side effects of the disease. My oldest sister and one other sister were later diagnosed and both needed transplants in their 50s, as I was at that time. Another sister won the “lottery” and was unaffected. The best part of this family heredity was having our own “support group” since there weren’t any public ones available at that time. For the next almost 20 years, I cruised along with high blood pressure and some urinary tract infections, but nothing else related to my kidneys.

One of the ethical issues I faced was in 2003 when my long-time and very distinguished nephrologist ended his patient practice to devote full time to his research. At my first meeting with the new nephrologist (one of his mentees who was petite and much younger), she immediately suggested an MRI. I was puzzled, but thought “Well, she’s just being cautious”. However, on our second visit she reported that my “kidney numbers” (mainly creatinine, which shows the level of waste products in the blood, and function) had been declining for some time and that I was getting close to needing dialysis or a transplant! I was shocked to learn about this decline, as I was completely unaware of this critical situation. On the way back to work that day, all I could think about was the “T” word and what that would mean to my very active and full-time work life. Here comes the ethical part. Two of the reasons I was so uninformed is first, I had not been keeping up with my kidney numbers (shame on me for not knowing how important it was), and the second reason was the patient communication style of my previous nephrologist. So, at my next visit with the new doctor, I asked her why I hadn’t been told about my worsening numbers and felt so blindsided by the news. Her response was very diplomatic and she went on to say that different

generations of physicians have different views on how much a patient should know about their medical conditions. Older physicians sometimes used a “don’t tell until it’s necessary” philosophy that shields the patient from bad news, especially since there wasn’t much to do medically about PKD. She noted younger physicians more commonly take a “keep the patient informed” strategy so that the patient can be more active in their medical care. You can bet I became much more active in all my medical care and let the professionals working with me know that I wanted to be included in all important decisions. So, which strategy, the former or later, do you think was the most ethical?

The next step was to find a donor, so I wouldn’t have to go on dialysis. But other ethical issues arose. How could I ask anyone to give up their kidney, undergo elective surgery, encounter risks, miss work, and convince loved ones it was a good thing to do? I found I couldn’t do it personally, but I did lean on my friends and colleagues to get the word out about my need.

Another ethical issue was the guilt of knowing that some people don’t have such a strong network of family and friends as I do who could advocate for them. Therefore, they are automatically disadvantaged. Since that time I have become an advocate for more equity in the identification, surgery, and recovery in the transplant process. My husband and I also encountered a blunder by the otherwise wonderful transplant team when he underwent an evaluation to be my donor. Despite the disclosure on his medical form and in his first two appointments with team members that he had had melanoma 20 years before, everyone assured him it wouldn’t be a problem. He got all the way to the final meeting with a surgeon (not mine to assure no pressure). He was told then that there was a possibility that he could pass on to me this tendency to have cancer, but they would leave it to us to decide whether to go through with a donation. One the way home, I told my husband there was no way we would do this and risk both of us getting cancer and not being there for our kids. As it turned out, my surgeon’s office called the next morning to say that the other surgeon had misspoken and the transplant team would not accept my husband as a donor. They

then sent us a couple of journal articles describing the instance where a cadaver passed on his cancer to donors. You can imagine how we felt about my husband going through the lengthy process and our hopes being built up and then dashed.

The other issue was that we were only a month away from my double nephrectomy and my only potential donor was now disqualified. My surgeon was worried that because of the frequent UTIs I was having, we should move on with the surgery even though my husband couldn't be my donor and no other donor was in sight. Our ethical dilemma then was how much noise to make with the team and what should we expect from them and the hospital? We were further outraged when the hospital began sending us bills for all the tests and appointments. I immediately called my surgeon's office and the billing office and said we would pay for the first two appointments, but nothing else since this issue should have been identified from the medical form or in his first appointments! Fortunately, all our bills were canceled.

After another colleague tried to be my donor, but couldn't, I found out in November that Linda had made it through the donor testing. What a wonderful day when she called me to tell me she had passed all the tests. Of course, we both cried and especially the next time we saw each other. I figured since she was an academic like me, she would want to do the surgery the following summer (2004) when we didn't teach any courses. She surprised me when she said let's do it as soon as possible. The next time off we both had was spring break, March 2004, and because I needed 4 months to recover from the nephrectomy in November 2003, it was perfect.

My next ethical concern was after the very successful transplant. The surgeon said, "It pinked right up" after they connected it. In the days before and following the transplant, I had been reading all the literature they gave me about the importance of taking care of Linda's kidney. The morning after the transplant, I woke with a feeling of huge responsibility. I don't know why I hadn't thought of it before, but that day it smacked me in the face and heart. How would Linda and I (and our loved ones) feel if I didn't take proper care of it? Luckily, I mentioned

my concerns to my surgeon when he came by for his post-operative visit. His first comment was, "Are you kidding me, Betsy"? He reminded me how consistent I had been in taking my meds, attending appointments, and keeping track of my numbers. He then said, "So after all that, do you really think you're going to fall off the rails and not take care of this new kidney?" Then we both laughed and I felt so much better to have my fears addressed. After a few months in the recovery process, I went back to work fulltime and have been healthy and hearty ever since.

When asked what I might want to pass on to transplant professionals, I immediately turn to psycho-social issues. One of the things I failed to do during the transplant process was to focus on my family and their needs. I did set up meal deliveries and a list for people to drive me to dialysis (my friends called it the "driving Miss Betsy carpool"). But what I didn't do was be aware of and sensitive to the needs of my family (husband, teenage daughter, and elementary age son). Forgetting that they had individual needs, I used brushstrokes to talk about the surgery and to put up a positive demeanor (my natural state). Therefore, I wasn't there for them, with everyone's focus on me. In hindsight I should have opened up opportunities to listen to their worries and concerns and do my best to address them. I would recommend for transplant professionals (not just the psychologist or social worker) to mention to donors and recipients that they think about keeping their family's needs in mind front and center.

My final dilemma was my feeling of extreme gratitude from receiving such a gift from a close friend and how to "repay" it. I struggled with the weight of the gift and thought I was the only one benefitting from my friend's sacrifice. Soon after the transplant, Linda sent me a card that helped me gain a sense of peace. On the front was a picture of a graceful, flying swan and the words "All that the human experience is about is the journey to wholeness." In the card, Linda had written, "You have said you will never be able to thank me. But I think the experience has been equally powerful in a positive way for me. Hopefully, my kidney will contribute to your physical well-being for years to

come. Taking this step to give it contributes to me in a more spiritual journey toward wholeness.” When I read those powerful words it was the first time I realized that the experience had contributed to her life too, so it eased my burden of insufficient thanks.

As a post-script, after 15 years of great health and fulfilled life with friends and family, my donated kidney began to lose function. Although I knew the typical life of a kidney transplant was about 15 years (kind of like an appliance), I had hoped I would be one of the 30-years folks. The call I feared the most was to Linda because I knew she would feel badly about her kidney. But I made sure to remind her of my 15+ years depending on her kidney with no dialysis needed.

Once again, through my friends they helped me find another donor, Tiffany Woynaroski, a colleague and fellow researcher at another university. We were scheduled to do the transplant in December 2019, however, I was hospitalized in November with a severe virus. I immediately had to go on dialysis and once that started, my liver began to leak a large amount of fluid. As they began to complete many liver tests, it was apparent the transplant needed to be canceled. It was very difficult to call Tiffany and tell her, because she was as anxious as I was to have her donate. Ultimately, I learned that I needed both a kidney and liver transplant. Because having a live donor for both organs was risky, particularly for the donor, I made the hard decision not to follow through with Tiffany’s offer. Eventually, after a year and a half on dialysis, I received another gift from a deceased donor and the surgery was on May 26, 2021. The recovery was a bit harder than I had anticipated, but now (September, 2022), I am back to work full time and feeling great. I am thanking my lucky stars that I have had two wonderful opportunities for multiple transplants.

Elizabeth co-authored the book, “The Insider’s Guide to Living Kidney donation: Everything You Need to Know If You Give (or Get) the Greatest Gift” with a kidney donor and her colleague Carol Offen.

## **From Coma to Kidney Transplantation: A Flourishing Journey**

Abdou Simon Senghor

Often called the “silent killer,” chronic kidney disease is difficult to diagnose until the patient is at an advanced stage when they experience symptoms such as nausea, high blood pressure, and fatigue. When I was in the third year of my sociology degree at university in Senegal, I had these symptoms, and the doctor at the social health center diagnosed chronic kidney disease. I had never heard of this disease, but I was not concerned and continued to eat food with too much added sodium. The doctor did not give me any information about what foods to avoid or how serious my illness was. Later, he would justify his silence by telling me: “I didn’t want to scare you.” His empathy caused my condition to worsen as the disease quickly progressed to the terminal phase, and I had to return home to Dakar.

A few months later, I was placed in an induced coma. According to my parents, when I was unconscious, the doctor wanted to classify me as a do-not-resuscitate patient. He thought that since my parents could not afford to pay for my dialysis sessions, prolonging my life would be against my best interests and those of my family members. My parents refused to accept his advice, and after learning that my university would pay for my dialysis sessions, the doctor agreed to treat me at the hemodialysis center. In addition to hospital care, my parents consulted traditional healers.

In Senegal, sick people are frowned upon, and belief in the supernatural causes of disease are genuine. Socially discriminating against sick people and judging their bodies have negative impacts. It was important to my family for me to improve my health and be less involved socially, which would allow me to avoid being stigmatized. The disease and its complications had transformed my body, and my parents did not want society to see me in this state, fearing that my interactions with society would worsen my medical condition. I was no longer allowed to go out with friends or participate in parties with young people. As you can imagine



going through such an experience was a shock for the young Senegalese attached to human warmth who I was even though it was no longer possible for me to go back to school or participate in social activities. All my social and leisure activities were confined to our house. Although sick, I benefited from the support and empathy of my family. With my family involved in managing the disease, I was better able to gain an empathic and emotional experience of my illness.

My position in the family also shifted; I was passive, dependent, and unable to have input in family matters. Therefore, my growth possibilities were limited. I no longer believed it was possible to have a social life or pursue my long-term goals. Furthermore, my parents made my re-entering of society conditional on protection—I had to agree to wear amulets to reduce the risk of attack by people and prevent my health condition from worsening.

My illness caused me to distance myself from my social environment. I had no control over this environment and avoided social contact to reduce risk and obtain my degree. When I returned to university, my peritoneal dialysis treatment took place at night. This allowed me to have the day free for activities. However, it came with constraints and choices; I could not afford to spend the night partying if I had class the following day. What this experience meant for me is that I had to choose which activities to continue and which to drop. Although this option allowed me to finish my master's degree successfully, I had to face reality because I eventually developed an infection. My medical team had informed me that peritoneal dialysis carried risks such as contracting an infection called peritonitis, an inflammation of the peritoneum. They had also taught me how to recognize the symptoms of an infection.

After I informed my doctors and nurses that I had an infection, they asked me to return to Dakar as soon as possible. I resumed hemodialysis and underwent several surgical procedures related to my infection. I also had several restrictions placed on my diet. Socially, I restricted my travel and stopped my studies again. With the difficulties incurred due to complications—and the social

exclusion imposed on me to protect me from the gaze and judgment of others—my parents and I doubled our efforts to find a country where I could receive a kidney transplant. Through my referring nephrologist, we contacted a hospital in Tunisia, but my parents could not afford the cost of a transplant there. Previously, my parents and I had asked for help from different organizations, but this was refused. Fortunately, one of my sisters was in Belgium at the time working for a Belgian doctor. He was sympathetic to my situation and created a charity to collect funds and bring me to Belgium. In the meantime, I applied for registration at a French university, hoping I could receive a kidney transplant there. It was this last step that succeeded.

The nephrologists I met at the hospital in Senegal influenced my decision to come to France as a student rather than a patient. They told me that young people on the waiting list for a kidney transplant had priority; This motivated me to get a French student visa, but my primary objective was to receive a kidney transplant. To avoid my health problems worsening due to a lack of dialysis, I immediately went to the social services department of my university in France and told them about my situation. They were astonished that a foreigner who had to have three dialysis sessions per week (with one dialysis session every two days) had taken the risk of traveling to France without first informing a hospital.

“How did you manage to come here? Why didn't you contact a hospital before coming to France?” asked the attendant.

They were surprised as traveling and spending days without dialysis could result in serious complications, even death. I had deliberately kept information about my illness to myself because I thought it might be an obstacle to entering France. The situation was resolved quickly, and I continued my hemodialysis treatment and my studies. I felt better in France; Hemodialysis prevented me from studying in Senegal, but I could renew my contact with society with the help of the students in France. However, even after returning to the classroom, I was still limited in other activities. I still had an arteriovenous fistula and could not go to the beach

or wear clothes that exposed my scars and swollen arm. I hoped I would integrate better socially after a kidney transplant.

The kidney transplant that I received 10 months after I arrived in France finally gave me hope for my future career prospects; I developed an interest in health issues and even dared to study my disease. Thanks to my kidney transplant, I obtained a master's degree in public health, wrote a sociology doctoral thesis on my disease, and obtained post-doctoral fellowships that allow me to further my work on health issues. Furthermore, I can travel, be part of associations, go out with friends, and participate in recreational evenings without worrying about going to the hospital for regular hemodialysis sessions or having my peritoneal dialysis at home at night. However, as a kidney transplant recipient, newfound freedoms sometimes create problems with the correct timing of medication; I go to bed late because I come home late from parties or work late on my articles.

Despite these drawbacks, I have built and improved relationships with others and feel less uncomfortable about my illness. I dare to have a purpose in life. My growth was possible because decisions were taken to invest in different care systems allowing me to achieve my goals while living with a chronic disease by integrating care into my social, personal, and professional life. In terms of my care situation, my objective, whether in Senegal, France, or Canada, was to achieve better health. Health management was essential and allowed me to reach my subsequent objectives, especially regaining my place in society, of which my illness had deprived me. With better health, I could reach my objectives of succeeding in my studies and research, working, and relieving my family of their financial responsibility.

In health management, different situations favor interactions between people arising in different social environments. The difference between these situations is the objective prioritized by the patient experiencing them. For example, the primary objective in the hospital was to treat me, but in their quest, health professionals quickly made the connection with my situation as a student and were able

to convince my parents to let me continue my studies at university. In my family, my primary objective was to have their emotional support and empathy to help me overcome this disease. However, I also wanted my family to purchase medication, be involved in my studies, and give me amulets to protect me from afar. My primary objective was to succeed when I started university, but I also needed good medical advice and monthly dialysis. Later, in France and Canada, my goal was to have a good semi-annual checkup, a reliable supply of immunosuppressive drugs after my kidney transplant, and continue my social and professional activities. This objective has evolved into a commitment to pursue research on health issues. For example, in Canada, I became involved as a patient partner in a Canadian network aiming to improve the quality of life and care of people with chronic kidney disease. Also, as part of my post-doctoral fellowship, I became interested in the ethical issues facing patients and healthcare professionals.

Considering this, health professionals working in renal transplantation must consider that patients are interested in transplantation because it allows them to flourish as human beings. It allows them to have lives that conform to their values, grow, accept themselves, take the lead, and make better decisions. Transplantation allows patients to integrate into society, achieve their personal and professional goals, and have positive relationships with others. In addition, an understanding of the experiences of kidney transplant patients may allow nephrologists to schedule medication times while taking into account patient activities. Therefore, kidney transplant professionals should consider all these aspects when assessing the preferences and needs of patients. Also, involving family actors could help them better understand the experiences of chronic kidney disease patients. Moreover, besides their expertise in kidney transplantation, transplant professionals could find partners in patients' relatives who could help them better understand patients' values.

## My Journey Through a Kidney Transplant Procedure

James Moran

**P**olycystic Kidney Disease is hereditary. My grandmother died at home before dialysis was readily available. My mother, uncle, and great aunt all had dialysis treatments for extended periods of time and eventually died. My uncle was most fortunate in that he had a heart attack while on dialysis. My mother and great aunt suffered through the disease before it consumed them. The magic age for adult onset PKD requiring dialysis is in the early fifties.

First diagnosed at age 25, I watched my creatinine levels increase over the years and knew what awaited me. I was 52 when my nephrologist said it was time for me to have the surgical procedure to attach a vein to an artery in my left arm. This arteriovenous fistula is the access point for dialysis. He said that I would probably need dialysis within about three months. It was about one year more before I really needed it. Even though it was an eventuality we had expected for over 25 years, my wife said: "I thought we had more time."

I considered myself fortunate to have dialysis available and so close. The center was about ten minutes from my house. The 5:30 AM appointment time was not my first choice, but it did enable me to continue working and still have evenings at home with my family. The initial few months are called the "honeymoon" period. Things were going well, I was tolerating the treatments, and I felt better. Why would I need a transplant?

I attended a pre-transplant session at a hospital at my wife's insistence. I really had reservations about the process. Except for the out-patient AV fistula surgery, I had not been "under the knife" and never had a hospital stay. A pre-transplant session at a different hospital was even more graphic and made me less enthusiastic.

Eventually, dialysis became more difficult and I felt more fatigued. It was more disruptive and vacations always created scheduling issues. Both hospitals as well as the dialysis team, encouraged

me to look for a live donor. They suggested that I contact family members and friends to tell them I was in need of a kidney donor. My oldest son who was 21 at the time offered immediately without being asked. Personally, I felt reluctant to put someone else at risk for me even though they assured me that the donor would remain safe and my outcome would be better. I reluctantly placed myself on the transplant list and received dialysis for about four years before a cadaver kidney became available.

The story of the call from the transplant clinic was interesting. My transplant surgeon had told me that I would need a bilateral nephrectomy because my polycystic kidneys were large and infected. He said that they needed to be removed before the transplant, but the removal should be delayed until I was closer to the top of the transplant list as it would add extra stress on my body. After about three years on dialysis, I received my first call. I declined the kidney and scheduled the nephrectomy. This surgery was difficult and I was in a lot of pain. The following year was brutal while I waited for the next call. Without my native kidneys, I was no longer producing urine and I had severe limitations on fluid intake. This was most unbearable during hot summer days. The long wait between the first and second calls was exacerbated by a nearby transplant center being closed as people transferred their wait time to the center on which I was listed. In the ideal scenario, I would have received a call soon after the nephrectomy had healed.

The second call came while I was on a Boy Scout camping trip. I had been involved in Boy Scouts for 25 years in varying capacities but many as Scoutmaster and frequently camping. I probably spent several hundred nights in a tent. On this trip, I had no cell signal inside the camp. My wife received the call at home and, after failing to reach me, drove to our camp and walked through the woods in the dark to find me. We were in a camp inside 25 square miles of forest. Fortunately, my wife is adept and has excellent outdoor skills. It was during dinner that she arrived. I remember turning around and being astounded to see her there. I didn't understand why she was there. I was still in shock when she told me about the call. The other leaders offered to

pack up my tent and bring it home at the end of the weekend. I picked up my backpack and started the trek down to the car. Another leader, ten years my senior, decided I was too frail and carried my backpack for me. I'm not sure why he thought I needed it carried down the hill when I had carried it up the hill. Perhaps my ill-health was more real now that the transplant was imminent.

When we arrived home, we waited for the follow-up confirmation call. When the call came, they said that this kidney was not for me. A month or so later, I received another call, and the kidney was a match. I think this is characteristic of the cadaver transplant experience. You wait, get excited, get let down, and then when you finally get the call, you're cautiously optimistic.

My son dropped me at the hospital and my wife left work to meet me there. They had asked me to come in the day before the procedure because we were expecting a blizzard that evening. I was relaxed in my hospital bed as I waited to meet my transplant nephrologist. She walked through the usual litany of things to be asked prior to surgeries, detailing all the bad outcomes, including death regardless of how small the probability might be. Wait, did she just say death? Yes, she did. Please sign here. I don't even remember being given *death* as a possibility when I had the nephrectomy, even though there's always that possibility. There's a certain point when you just must put your life in someone else's hands, and there's no turning back. I know. It's scary.

The next morning, I was prepped for surgery. As I waited on a gurney to be taken into the operating room, the anesthesiologist came to visit and described how he would induce sleep and keep me comfortable throughout the procedure. When the surgeon came, I asked him: "Is this the right kidney for me?" He replied with a smile: "Yes, it is."

The transplant surgery went well. I remember waking up in the recovery room and had minimal pain. I asked: "Am I peeing?" I've heard that kidney transplant doctors refer to urine as "liquid gold," and I was producing it. It's common in some situations for the new kidney to take a little time before "waking up." That was the case for me. I needed

one dialysis treatment before it woke up and started doing the job that my body had not done naturally for four years. I was discharged in less than a week and began the next journey.

Unfortunately, I returned several times in the next three months with infections leading to sepsis and pneumonia. These months were very difficult, and I was questioning my decision. However, the persistence and support led me to a successful outcome, for which I am grateful. In spite of these difficulties, I would do it again even with the possibility of similar infections. On a side note, a friend received a transplant from a living donor about one year before I did. We were both outliers, but on opposite ends of the spectrum. His transplant was absolutely perfect and he has had no problems in 9 years. There are always risks, but also benefits. I am typically risk-averse, but I would take this risk again.

Due to the multiple infections, my transplant nephrologist expected this kidney to last between only one and three years. I am now 8 years post-transplant and stable with the same kidney. This is also 12 years since the inception of my dialysis. At that point in their lives, my mother was on life support, my uncle and great aunt had died. The math is simple: I'm alive, but not only that, I'm not anchored to a dialysis machine three days per week. Aside from the physical aspects of a transplant, I feel it has made me more tolerant of difficult situations and grateful for simple things.

I cannot say enough good things about my transplant team. It is difficult for me to comprehend how many individuals were involved in this process—surgeons, doctors, nurses, aides, social workers, dieticians, pharmacists, physical therapists, phlebotomists, maintenance staff, plus others I've inadvertently omitted. It is truly amazing how each person expresses so much care as they attend to their patients. I am in awe.

An illness is not something that affects just one person. It affects their spouse, family, friends, and colleagues. I am very grateful for my wife, who spent many nights with me in the hospital, cared for me at home, and encouraged me to get through the difficulties. I cannot imagine how this would have played out without her support.

I'm also grateful to the group that has opened this narrative. Too many people are unaware, and frankly, my medical self-awareness and knowledge were not the best. They have improved during this process. I'm still astonished when people ask inappropriate questions or make inaccurate statements about the need for transplant, the expected outcome, and life after transplant. It's not that I need them to "walk a mile in my shoes," but a little knowledge of the process would lead them to a better understanding. Medical science has advanced greatly in my lifetime. That leads to expectations and assumptions that might not be true. We all need to be aware that it is still a magical process and is brought to reality by dedicated people.

While some people's comments and questions may be inappropriate, there will also be offers to help. Most of these will be generic ("How can I help?"). It helps to enlist a close friend or family member as your help coordinator. Many generous people have cooked, shopped, and chauffeured for us. It is a great comfort knowing that some things are handled while you're ill. I have also participated in helping others in similar situations and can attest that it is a gift for the giver when someone coordinates concrete ideas for support.

Your mileage may vary . . . and I hope it does. The probability of infection is low, but informed consent is exactly that—you need to be given more than the rose-colored view of the perfect outcome. Everyone is unique and their experiences most likely will be different from mine. The exception is the cadaver-donor roller coaster. Until implantable manufactured kidneys become a reality, there will be a waitlist. Even then, production costs or supply chains may limit the accessibility to the general population. In the short term, we need more transplantable organs. Everyone can help by signing an organ donor card. If you feel inclined, you can gift an organ to a recipient in need. If you are waiting for an organ, take a deep breath because one of those coaster tracks will level out, and your organ will be there.



## Today We Walk. Tomorrow We Dance

Allen Callaci

**R**oughly 10 years ago I was helicoptered from my local community hospital to Cedars-Sinai with less than a 25% chance of surviving the brief flight. I left work early, not feeling well that afternoon, and shortly after arriving home, blacked out across my bathroom floor. The heart that had been beating inside me for 40-plus years was in complete collapse. After more than 40 years, it was discovered that the circumflex branch of my left coronary artery had been underdeveloped since birth. My other arteries overcompensated over the ensuing decades, which slowly wore my heart down.

I was tired in the years leading up to my transplant but I attached that weariness to my rich and active life, which was filled to the rim with working two jobs, being a grad student and occasionally singing in a rock 'n' roll band.

They say life changes in an instant. Mine changed quicker than that. I left work that afternoon thinking I'd be back in a day or so and catching a Bruce Springsteen concert I had tickets to the following week. Instead I woke up in a hospital bed hooked to oxygen and the symphony of a beeping heart monitor, connected to 27 IVs and two heart assist devices attached to each side of my heart. I woke in a medicated fog with my sister mentioning I was going to be having a heart transplant. I wondered if my situation was real or if I was dreaming and had been swept to a hospital located in Oz.

The most positive and painful moments of my recovery and quest to get back home could sometimes be part of the same moment. There were excruciatingly painful moments as I balanced myself on a walker surrounded by a pit crew of nurses helping me balance all the IVs and an oxygen tank. One of the crew followed close behind me with a wheelchair if I should tire on my trek around the nurse's station and should need a rest.

Having not walked in weeks and weeks, each step was excruciatingly painful. My legs felt like a pair of wet flimsy noodles as I stood up for the first



time in a month and a half. My mind knew exactly what it was supposed to do, but the body wasn't getting the message

But as painful as these steps were (and they really were), I saw each step as one step closer to home. The staff at Cedars-Sinai were not just staff taking another patient on a walk—they made me feel like they were my crew with their reassuring and positive attitude as they guided me. I'll be forever grateful to the nurse who, on one of my first brutally painful walks around the nurse's station, lightheartedly told me that "today we walk, tomorrow we'll dance." I've known fewer moments as hopeful, humorous, and humanizing as that one. That mindset transferred onto me as we made our daily walks around the nursing station. Those walks became less and less painful with each passing day. I saw my progress as I graduated from walker, to cane, to being able to walk independently again.

I have not stopped thinking of my donor and their family in the years since returning home from Cedars-Sinai, although I only know minimal details about them. I know they were 25 years old and a male. I have reached out to the family with written expressions of my enduring and unending gratitude over the years through the proper channels but have yet to hear back. When I sent out my initial note to the family, I was told that the odds were that I would likely not hear back as it can be an overwhelming emotional experience for donor families to meet the donor. This is more than understandable. My hope is only that my donor family found some small comfort and a sense of closure in my messages.

I am often told by others what a journey I have been on. And it has been a journey. But it has not been my journey alone. It is one that has included many others—family, friends, co-workers, physical therapists, transplant coordinators, and of course, my donor and their family. If there is a profound secret or grand takeaway for me to pass along to others who may ever find themselves in a similar set of circumstances, it would be this: to not lose sight of this on your own individual journey, especially during those passing moments of doubt and

despair. It is not easy, but it can be done. And it can get done one day, one breath, and one step at a time.

Yesterday I walked. Today I dance.



## Perspective and the Gift of Life

Todd S. Frantzen

My transplant story is that of a famous Dickens quote, "it was the best of times, it was the worst of times." The best is that I am alive to tell my story; the worst is the toll it has taken on my loved ones and myself. I had not been feeling well for some time and knew something was seriously wrong with me. I had just moved to California and knew I could no longer ignore my health, so I found a primary doctor, and my suspicions were confirmed as my doctor referred me to a liver specialist. I saw the specialist every two weeks for six months to have blood drawn and he monitored my Model for End-Stage Liver Disease (MELD) score. He explained to me that I was experiencing liver failure.

In October of 2014, I received a letter from my liver specialist informing me that without a liver transplant, I had at best three months to live. With this information, I had to decide what was my next step. In many ways, nothing changed. I continued to go about my daily routine of running a household, attending graduate school, and feeling unwell. At this time, I was 51 years-old. Part of my reflection was, "Did I live a good life? Do I want to receive a liver transplant and deprive someone younger a chance at life? What if I go through with the transplant and I die anyway?"

For my wife, there was only one option: to move forward and take the three-day intensive physical and mental evaluation required to determine if I even qualified to be added to the liver transplant list. So, that's what I did.

During this evaluation, a biopsy was performed on my pancreas. This biopsy went terribly wrong.

My pancreas was severely damaged to the point that my blood sugar level was over 600 immediately after the procedure. I was rushed to the ER. I am a diabetic to this day.

I was ultimately included on the liver transplant list, but I still had my doubts and started to put my affairs in order. Over the next year, the bad days far exceeded the good days as far as my health was concerned. I had more hospital stays as my health continued to deteriorate. My MELD score was consistently around 25; living in California, I was told the MELD score needed to be at 40 before I would be at the “top of the list.”

By December 26<sup>th</sup> of 2015, my MELD score was over 40, and I was at the top of the list. It would be only a matter of time before the transplant. By then, my kidneys had failed and I was on dialysis. I was very sick and went unconscious. (The unconsciousness lasted three months.) As donors became available, it was decided that my heart would not be strong enough for the transplant surgery, and in fact, I was suffering from congestive heart failure.

The liver transplant team, the heart transplant team, and the kidney transplant team met with my wife and told her that I needed a heart, liver, and kidney transplant. Up to this time, my wife was told there were only five such operations that had been performed involving these three organs. The ultimate decision to move forward with the operations was made by my wife—a situation I never wanted to put her in—but which was unavoidable due to my unconscious state.

The day of the triple organ transplant surgery was February 10<sup>th</sup> of 2016 (Ash Wednesday). The heart transplant went well. The liver transplant was unsuccessful. The artery that delivers blood to the liver collapsed, and the transplanted liver was not receiving blood. Within hours I was relisted for another liver transplant. The kidney transplant was also unsuccessful and I remained on dialysis for two years. After the surgery, I developed sepsis and had numerous setbacks leading up to the second liver transplant a month later.

I stayed in the ICU for six months and spent another three months at the hospital before my doctors declared it was time for me to go home. The

problem was I could not walk, talk, eat, move my hands, or stand up straight, all collateral damage from my surgeries. I had suffered a fractured back due to a technician putting a board behind my back to take an x-ray of my abdomen. I still use a walker to this day to aid in my mobility. I was receiving physical and occupational therapy throughout my hospital stay; however, it was not enough. I was transported from the hospital to a rehabilitation facility, where I spent six weeks learning to swallow, eat, talk, stand, walk, and move my body. For the next year, I had physical therapists, occupational therapists, and speech therapists come to my home until my immune system was strong enough for me to receive this therapy outside the home.

The kidney transplant was not a success, so I was going to dialysis twice a week. Dialysis was one of the most difficult experiences of my life. The drain on my body and emotions left me in a state where I felt I would never get better. My wife continued to do research and uncovered a policy change that effectively stated if you had a kidney transplant and it never worked, you could relist within a certain time frame. We spoke to the kidney transplant team numerous times and were very disappointed with them as they never brought up this policy change. The kidney transplant coordinator even told us we are educated people with financial means, and we should go it alone to get relisted. Having spent so much time in the hospital, we learned that the squeaky wheel gets the oil, so we went to the head of the kidney transplant team and he relisted me for a kidney transplant. The second kidney transplant occurred in December of 2017 and was successful.

Unfortunately, this is not nearly the end of my story. With the passage of time, the collateral damage was adding up. My heart, liver, and kidney are all working fine right now, but the extended hospital stay and the effects of the medication I take (and will take the rest of my life) have had an effect on the rest of my body that I could never have imagined. I have osteoporosis and am prone to bone fractures. Along the road of recovery, I had broken my shoulder and hip, had numerous back fractures, and even lost four inches in height. I am

prone to skin cancer and every three months, I meet with my skin cancer doctor and go under the knife. My feet were deformed from the long hospital stay and I underwent a surgery on each foot to provide a temporary solution so that I can walk. My fingers are deformed and I have back issues. My transplant doctors advise against surgery. I even had appendicitis and an emergency appendectomy. The ability to taste, smell, run, jump, and grip objects have all been lost. I live in a constant state of pain, and due to my transplants, I have little to no pain management options. Sleep is a word that is foreign to me.

Self-reflection never ends. Why am I here? What did I do to be the recipient of this chance at a second life? All that I have been through, people have asked me has it been worth it. Would I do it again? For me, it all comes down to perspective. My doctors refer to me as the “miracle.” I don’t know if I am a miracle, but my faith tells me I have a purpose that I need to fulfill. I am still on the journey to find that purpose. Without the pain, I never fully knew the gift of life. My story and the ultimate gift of organ transplants gave me a second chance to live, but more importantly, it taught me the true meaning of love and sacrifice.

In the beginning of my illness, family and friends supported me with words of encouragement and an outpouring of love. However, as time moves forward, so have they. My relationships have changed. My mother and brothers act as though nothing has happened to me and don’t quite understand my limitations and why I am not the person I was before my illness. Close friends have strayed and do not know how to communicate with me. For many of them, it’s from fear of their own mortality. There has been one true constant in my life and that is my wife. When I look in the dictionary for the word love, I see a picture of her. She was my voice; my champion; she fought the medical system to ensure I had the best care; she has never left my side. She is my pillar of strength and makes me push through the pain to live the best second life that I can.

Receiving the gift of life is something I treasure every day when I put my feet on the ground, knowing that I have another day to share with my wife and family. My life-long philosophy is to never look

back but to always live in the present and dream of the future.



## The Right Heart

Ingrid Gould

I remarked to a friend, “We haven’t spoken since my arrest!” Alarm and confusion clouded his face, given my half-century of squeaky-clean living. “Cardiac arrest,” I clarified. “The fire department rebooted me.”

An electrophysiologist diagnosed Arrhythmic Right Ventricular Dysplasia, prescribed medication, and implanted a defibrillator. For the next three-and-a-half years, he helped me live with a disease I didn’t know existed until he told me I had it.

The disease *progressed*—an ironic, disease-centric term since *its* advancement was to *my* detriment—prompting my cardiologist to recommend seeing someone who specialized in heart failure. I resisted the very idea of heart *failure*, a terrible term for a struggling organ, but took her advice and scheduled an appointment.

The new cardiologist urged transplant testing, a lengthy process. I agreed, figuring that by the time I needed a new heart in 15-20 years, they’d be rolling off 3D printers.

To record occasional transplant musings and inchoate fears and perhaps, over time, untangle them, I began journaling. I chronicled my passage through the echocardiogram, heart catheterization, 31 tubes of bloodwork, interviews with different clinical specialties, a pulmonary function test in a machine reminiscent of Star Trek’s Transporter, and more. Testing had barely begun when my medication stopped working—a Halloween shock.

I began a harsher medication, underwent an ablation, and spent six weeks in a wearable defibrillator, a vest with abundant wires, and a purse-sized battery pack that made me resemble a character in



the Jetsons. This attire did not bring holiday comfort or joy to the TSA<sup>1</sup> when I flew to visit my sister. As my R-waves faded to a whisper, I swapped the vest for a second implanted defibrillator, substantially more sensitive than the first.

In early 2018, we learned I had qualified for transplant listing, though I wished to get as much mileage as possible from the original engine. My cardiologist warned, “There is no Plan B—no machine, device, or medication for the long-term. You will need a transplant.” He explained that since most cardiac patients have left-heart problems, companies develop products for the left side of the heart. My problem was on the right—a tiny market. He also cautioned that a patient needs to be sick enough to warrant transplant and well enough to remain a candidate, survive the surgery, and recover.

Although clinically I was ready, I was not personally ready. I felt too good to trade an excellent quality of life for the promised miserable post-transplant year. The cardiologist wisely asked if I wanted to speak with another patient. When I requested someone beyond the dreaded first year, he put me in touch with two women who had received new hearts a few years earlier and befriended each other. They soon became my invaluable mentors and cherished friends. I will never forget seeing them stride into our first meeting and thinking, “They are beautiful! They look totally normal!”

By May, climbing four flights of stairs took as much effort as five used to take. Tests confirmed further deterioration and suggested I had 7-13 months of declining health before my heart would give out completely. We chose a date for hospital admission, and I started telling people outside my immediate family. Most were flabbergasted, believing heart transplants were the last hope of the desperately ill. I did not look moribund, though, apparently, I was.

The eight months after my first transplant appointment let me prepare psychologically to bid farewell to my heart—the metaphor for kindness, love, and bravery in our culture—and to welcome

a new organ from a generous person less medically fortunate than I.

In the hospital, I met others awaiting their hearts. A sudden intimacy arises when mortal choices catapult people into a medical realm suggestive of science fiction. Add the emotional intensity that accompanies knowing your extended life comes courtesy of a person who breathes no more on this earth and you wonder how an organ recipient integrates sorrow and gratitude.

Two weeks after I was hospitalized, my cardiologist informed me the wait was over. Not long after midnight, when I kissed my husband before being wheeled into the OR, I never doubted that I would see him in my room in a matter of hours. I was in awe of my surgeon, who seemed part human and part divine.

Later that day, I awoke hazily in the ICU, soft-voiced, having been intubated and tender-chested from being recently sawed open.

That first night, machines whirred on both sides, multiple bags dripped into me, lights blinked, screens displayed the healthy rhythm of my new heart, alarms chirped occasionally, and leg massagers squeezed and sighed to prevent blood clots while soft conversation snippets drifted from the hallway. Tubes, wires, bandages, and equipment constrained my movements. A knocking, absent during the day when people filled my room, echoed in my head as I tried to fall asleep. When I looked left, the sound emanated from that direction. When I swiveled my head right, the sound materialized on the right. Gently searching for the sound’s source, I realized that when I faced the ceiling or raised my head, the sound vanished. Suzanne Vega sang the truth: Blood makes noise. With a healthy heart beating in my chest, blood coursed distractingly loudly throughout my body and in my ears.

My first post-op adventure? Sitting up in bed. Next the nurses let me dangle my legs over the edge like a child. When permitted, I stood. Flanked by two nurses, I walked three feet to a chair. In that chair, I fed my new heart its first solid food in my body. Later that day, I walked a quarter-mile with my nurse, IV pole, incision drain, precautionary external pacemaker, and heart monitor—more accessories than usual.

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<sup>1</sup>The Transportation Security Administration (TSA) is an agency that has authority over the security of people traveling by air in the United States.

Five days later, I was transferred to post-op cardiology and greenlighted to walk unattended. My friends and family sent messages and visited, bringing food, books, and heart-themed gifts. One told me about his uncle, who flourished for decades with a transplanted heart. The physical therapy team taught me how to move, exercise, and stretch properly for my healing body and new heart. Daily rounds brought the surgery and transplant teams to check on me and advise on both test results and upcoming procedures.

In the hospital, I observed those who cleaned and bleached my room, drew blood, took meal orders, delivered food, and wheeled me to and from tests. For someone immunocompromised, cleanliness is next to godliness. The needle pricks less when the phlebotomist calls you “baby.” Nourishment comes in many forms. Numerous workers provide health care.

Once back home, I marveled that the nurses had infallibly dispensed my complicated and changing medications. Despite an hour-long training session with a pharmacist, I struggled to fill my pill-holders, triple-checking the multi-page medication spreadsheet sent home with me along with discharge instructions in a 113-page transplant guide. Some recipients refer to that guide as the Bible. Wags call it “The Book of No”. After reading it several times, I christened it “The Owner’s Manual”.

A transplant recipient is most vulnerable in the first year. The team watches vigilantly and tests often to ensure the immune system is suppressed enough to prevent rejection. Back and shoulder pain, intense headaches, debilitating muscle weakness, and hand tremors characterize the initial 3-6 months. Infection or rejection may necessitate hospital readmission. Those perils did not materialize for me.

People often ask, “What’s different now?” Some limitations last for three months, some twelve, others a lifetime. I eat salads again but not sushi. I abandoned the “five-second rule.” Sunscreen figures into every day. Although lakes are too bacterial for swimming, oceans and chlorinated pools are fine. My complexion is now so rosy that my oldest friend asked in utter perplexity, “When did *you* start wearing makeup!”

We expect life-and-death events to transform us or grant keener insight, a greater sense of mission, wisdom, even transcendence. My trusted transplant team focused on physiological realities, prepping me for the practical: dietary restrictions, medication regimens, frequent appointments, avoiding anyone contagious, and a year-long travel ban so that at the first hint of a serious problem, I could be whisked into the hospital—their hospital.

An unexpected boon of my transplant experience is an abiding sense of community. One hears about aversion to illness and anxiety about saying the wrong thing to someone sick. My community and I learned together that an acute medical situation can lift inhibitions about expressing concern, affection, and love, thus deepening, accelerating, and even forging new relationships.

Perhaps more than revising habits and enjoying enhanced relationships, I needed to update my understanding of myself and my “self.” I’d spent my life striving to be strong and resilient. I never dreamed that a doctor would declare: “You are fragile!” This refrain contradicted my concept and construct of self. While I balked at considering myself “fragile,” I could accept myself as “more fragile” and settled there.

The question of “self” lingered. An original, “factory-issued” vital organ was expertly removed, and another person’s heart stitched in, vessel by vessel. I became a chimera, a mythological creature science appropriated to describe a genetic mixture. One transplanted friend awakened from surgery craving chocolate milk. She later learned her donor adored chocolate milk. Would my donor’s preferences similarly assert themselves?

Every night as I listened to the percussion of my heart against the pillow, I wondered how my heart had lived. Did it sing with the radio? Excel at sports? Laugh at corny jokes? Read mysteries? Stay up late? Were these questions borne of pure curiosity, or could I do something to make my heart feel more at home?

After studying the dos and don’ts for writing to a donor family, I sent my condolences, thanks for their gift, and assurance that I was doing my utmost to care for it. My transplant friends had reported

lengthy silences. I received no reply. Fearing that I'd offended the family, I reviewed my letter, imagining myself the grief-stricken reader. Had I salted their wound?

The agency that supports organ donations helped by calling the family; my donor's sister swiftly released her contact information. Two and a half years after my surgery, she and I had a tender and tearful phone call. The next day, I met my donor's parents and siblings on Zoom.

The technology cooperated, though we felt a bit frozen—stunned and tongue-tied. As with much of this transplant experience, the family and I had no script, no dress rehearsal for our meeting. Long imagined words vanished. Zoom diminishes facial expressions, and the pandemic challenges in-person contact. We sensed the deep biological connection, while we were also perfect strangers. If we had passed on the street, we would not have recognized each other—though we might wish to have imagined an inexplicable double-take, a metaphysical *déjà vu*.

The sister's grace and warmth broke the ice. My Argentine-accented Spanish came in handy with my donor's Mexican-American parents. All lingering ice dissolved. Conversation and stories took off, our topics ricocheting from the profound to the mundane. The family's love for the vibrant, "siempre feliz" woman who became my donor was so palpable that I feared my presence would exacerbate their loss. Instead, they generously told me that my donor liked helping others, and it comforted them that a physical part of her was still living. As if delivering a blessing, her father exhorted me to live a long, healthy life and enjoy my heart, the best part of his daughter.

Our meeting felt like a reunion of strangers linked by a beautiful heart. Our connection vaulted the family into their relative's present, revealed my heart's history, and offered us a shared future. As the Zoom ended, my donor's sister said, "When we do get to meet in person, we will all want to hug you."



## A Trial of Patience

Christopher Lewis

It seemed like after two weeks, my "flu" symptoms should have resolved. I was not eating, could not hold anything down, and had no energy. It was easy enough for my pediatrician at the time to attribute this to a common virus. This was not sitting well with my parents, however. My mother decided to take me to the emergency room and get me evaluated there. The doctors there assessed me and sent me back home with a medication to help with the nausea. Later that evening, my mom gave me that medication, and it caused a seizure. She called 911, and I was brought by ambulance to the hospital. After an extensive workup, it was determined I was in liver failure related to an aneurysm in my hepatic artery. I was going to require a liver transplant if I were to live. I had to be transferred to another hospital in New York from the hospital near our home in Connecticut. I do not remember any of the details leading up to this after the seizure. I do not remember being told I needed a liver transplant and I do not remember going into surgery.

My memories of these events start after the surgery. What I remember is being in the pediatric ICU and being told my mother was able to donate part of her liver to me. I had quite a lengthy recovery after this point. I spent about two months in the hospital and then went to a rehab facility where I would have to learn how to walk again and regain my strength.

By the time I was discharged from the rehab facility, I had missed the last half of my 5<sup>th</sup>-grade year. By the time I was able to return to school, it was already several months into 6<sup>th</sup> grade. Slowly but surely, life was returning to normal. I was able to get back to doing the things an eleven-year-old should be doing. For twelve years after this initial transplant, I was in great health, my transplant team was happy with how I was doing, and I just required annual checkups after a while. Unfortunately, I saw as a child how fast things can change. This was once again the case.

I was in my last week of college classes, just about to finish my Bachelor's degree in nursing and looking forward to starting my career as a nurse in the neuro ICU. However, I once again became acutely ill with seemingly flu-like symptoms. After a few days of dealing with these symptoms, my mother brought me to the emergency room. When we got to the emergency room, they did some initial testing and told me I would need to be admitted for antibiotic therapy. The first thought that came to my mind was, "Would I be able to be discharged in time to take my final exams next week?"

Once I arrived in my hospital room, I met with my transplant team. They delivered the grave news. The imaging they had done showed that the graft artery from my original liver transplant as a child had failed. The graft had thrombosed and I had infected bilomas in my liver. Now, twelve years later, I would need to be re-listed for another transplant. I was devastated and in disbelief. I recall telling my mother, who was with me at the time, that we should hold off on telling my dad, thinking this could not be possible, and we shouldn't worry him over something that was not necessarily true. Unfortunately, however, this was my reality. I would go on to wait a little over two years for the perfect liver from a deceased donor.

The road to being listed and ultimately having a repeat transplant was not without its challenges and bumps in the road. About three months into my two-year wait for a liver transplant, I received my first offer for a liver. I went through all of the pre-op preparation and the next morning went into the OR and underwent anesthesia. However, I woke up still down in the OR. I knew something did not seem right. Everyone was silent. It was explained to me that the transplant would have to be canceled because one of my blood tests came back positive for an infection. This was devastating to my morale at that time; however, my transplant doctors were still very optimistic going forward. This helped me bounce back and keep a positive attitude until another offer became available.

Shortly after my almost transplant, a new complication was added to the mix. It was now discovered that my portal vein, which is responsible

for supplying the liver with most of its blood from the stomach, intestines, and pancreas, was also occluded. It would not be just as simple as a liver transplant. I would now require a multivisceral<sup>2</sup> transplant. As my transplant team explained more of the situation to me, it was also made clear that the center I was at did not offer multivisceral transplantation. I would have to be re-listed at a new center over 300 miles and about 6 hours away from my home. I felt defeated. It seemed like I was further from getting through this than I ever had been. My family and I drove down in the coming weeks to the new center and began the process of getting myself re-listed, this time for a multivisceral transplant.

We met with the new surgeon, and he explained the process of having a multivisceral transplant in more detail. It was more intense than I had anticipated. It involved a longer recovery, higher risks, and I would have to live by the transplant center for several months after transplant. The surgeon answered all of our questions, and I felt reassured by his level of knowledge and warm demeanor. We left the visit, and after several other appointments and tests—and one additional visit to the center—I was now listed for a multivisceral transplant. The hard part was now about to begin, the waiting.

Almost a year had gone by since our first visit to the new transplant center and I had not received so much as one potential offer for a transplant. I was beginning to lose hope and did not think I would ever receive a multivisceral transplant. I had made up my mind. I was going to tell the new transplant team that I did not care about the risk—I wanted to pursue solely a liver transplant and abandon the idea of a multivisceral transplant. I was not sure how they would react to my idea. When my family and I next went down for an appointment, I brought up my idea. To my surprise, the idea was not met with a stark no. The surgeon explained that if I was dead set on this idea, we should obtain a portogram,

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<sup>2</sup> A multivisceral transplant is one in which the intestines are replaced, along with the liver, spleen, and sometimes the stomach.

which was a minimally invasive diagnostic procedure in which they could better visualize my portal vein. That set things into motion. The portogram was scheduled and in a few weeks, I would come back for the procedure.

When we returned for the procedure, I felt anxious—not for the procedure itself, but for the results. I had put all my hopes into this portogram having a favorable result, and providing the surgeons with the confidence that a liver transplant could be performed instead of the multivisceral transplant. I was brought back into the procedural area, and before I knew it, the anesthesia had kicked in and I was out. In what seemed like an instant, I felt myself slowly waking up. The first sense that I remember coming back to me was my sense of hearing. I heard voices talking about how the procedure went well and had the results I was hoping for. It was looking like an isolated liver transplant would be possible once again. Now the next step was to get re-listed at my original transplant center. When everything was complete, I was able to be listed at both centers, increasing my chances of finding a match for a transplant. There was still some risk with doing an isolated liver transplant because I was told although the portogram results showed the portal vein looked patent with good blood flow, until the surgeons actually visualized it during the transplant, no one could be one hundred percent sure. I know at the time that multivisceral transplant was the safest option to pursue. Both teams had the best intentions and wanted the best outcome for me, but I am glad looking back that I advocated for myself to pursue other options.

Once I was re-listed for an isolated liver transplant, it was about two years of waiting until the perfect liver for me had become available. It was hard to believe. The news was brought to me by a medical student. Shortly after, the surgeon who did my original liver transplant came in and went into greater detail. (My original transplant surgeon had relocated from New York City where I had the first transplant to my home state of Connecticut not too long after my first transplant.) After a little over two years of waiting, my original transplant surgeon happened to be the surgeon on service that week, bringing me the news. Everything felt like

it was falling into place. My transplant team had always told me that this day would come, but I could hardly believe it now that it was here. It was a mix of many emotions. I was excited for myself, sad for the family that had lost a loved one, and nervous about the surgery.

The surgery took place the next day. I was told it was about a twelve-hour surgery. After that, I remember coming in and out of consciousness while recovering in the ICU. I just remember being told that everything could not have gone better. I was on the road to recovery. I spent about two weeks in the hospital afterward and had a very smooth recovery. Once I was discharged, life slowly started to return to how it was prior to becoming sick.

It has been about two years since I've had my second liver transplant. I'm thankful every day. Thankful for my family and friends who supported me and thankful for my transplant team, who guided me the whole way. The level of compassion and expertise I experienced from my transplant team is unmatched. They always explained everything clearly and in great detail and made sure all my questions were answered. They would take a seat in my hospital room and tell me their plan during their rounds when I was hospitalized and in the clinic for follow-up visits. Most of all, I am grateful for my donor and her family, whose selfless gift has given me the ability to live a healthy life every day. Through my regional donor organization, I was able to exchange a letter back and forth with my donor's parents and learn a little bit about her. It is my hope that I can live in a way to honor her. Since my transplant, I've been able to start working as a nurse in the neuro ICU, at times caring for patients that go on to become organ donors. It has been my goal to have an impact on my patients and families like my nurses and doctors did for me. I have also been accepted to the nurse anesthesia program at the hospital where I had my transplant and where I work. I could not be more excited for this next chapter. All of this has been possible because of the gift from my organ donor and the dedication from my transplant team.





## The Transformative Journey of Transplantation

Valen Keefer

The moisture from the ocean floated effortlessly through the air as it glided over the rocky cliff. The steady stream of mist covered my face and frizzy hair with beaded water droplets. I had been sitting on a bench alone for hours admiring the Northern California coast at a magnificent overlook featuring a bird's-eye view of the endless sea and campground I called home for the past month. The stunning mountain landscape behind me, the soothing colors of the coastal shrubbery, and the smell of eucalyptus made for a trifecta of surreal beauty. The ocean disappeared from my view and I became engulfed in the precipitation and felt like I was suspended in a cloud. I was soaking in every moment as it was the last day of my solo RV trip.

The fog slowly separated and exposed bits and pieces of the ocean again and then a breathtaking rainbow came into sight. Each end appeared to be touching either side of the campground like it was giving it a hug. I was eye-level with the center and highest point of the rainbow, arching above our home on wheels. I stood on the bench with my arms wide open, embracing nature and the gift of life in all its glory. This moment would not have possessed such deep meaning if it wasn't for the journey that came before it—the transformative journey of transplantation.

Some may think of transplantation as a singular event when in reality, it's a lifelong journey that can start with a diagnosis many years prior. My transplant journey began when I was diagnosed with polycystic kidney disease (PKD) at 10-years-old. Being diagnosed with a hereditary disease that has deeply impacted multiple generations of our family and with no known treatment or cure was a lot to carry as a child.

My youth was full of love from my parents and filled with illness and the limitations and long-term impacts of growing up with multiple chronic illnesses. My education on PKD was the brutal real-life experiences of enduring it firsthand—with no support groups, resources, or internet to seek

answers. I always felt different during a time when you'd do anything to fit in. I couldn't play sports and had to sit on the sidelines in gym class. I was often in the nurse's office, hospital, or recovering from a surgery. I hid my scars and unattractive body while changing in gym class. Friendships were really hard. Relationships were even harder.

Growing up with chronic illnesses takes away from the fun of dreaming. It's like that bright future full of endless possibilities is blocked by a huge mountain you know you have to summit first with no supplies, no friends, and no paved path to follow.

Complications from PKD followed me from high school right into college, when I spent almost a year in the hospital. Both of my kidneys were removed, I was on dialysis, had pancreatitis, received over 70 blood transfusions, survived an internal bleed, and was in dire need of a lifesaving kidney transplant.

At 19-years-old, I was too sick to be placed on the transplant waiting list, but needed a kidney to survive. My parents were living at the Ronald McDonald House, wondering if they would be the next ones to lose their teenage daughter. A close family friend forever changed our lives when she restored my health by selflessly donating her kidney to me. While it was an arduous path to transplantation, in some ways, the journey was just beginning.

Fifteen years following my kidney transplant and summiting what I thought was going to be the most challenging mountain of my health journey, I found myself back on death's doorstep with another battle ahead. I was in need of a second miracle, this time a lifesaving liver transplant. It was PKD again. The bile ducts in my liver were so gnarly that they looked like limbs of an oak tree rather than the desired smooth straw-like appearance. Their malformations led to chronic liver infections and multiple sepsis episodes. I was receiving daily IV antibiotics, and was so ill that I became number one on the transplant waitlist at a hospital in St. Louis. My husband and I temporarily relocated from our home in California to Missouri to wait for "the call." This time it was a selfless stranger who restored my health. Because they said "yes" to organ donation, I was given a second, second chance at life.

August 2022 marked my 20-year kidney and 4-year liver transplant anniversaries. This second

half of my life would not have existed if not for my two donors, my incredible healthcare teams, and all who supported me through this remarkable life. The ripple effect of good that has come from organ donation is awe-inspiring. My parents were given their daughter back. I was able to fall in love, marry my husband, travel cross-country together, and move from our home-state of Pennsylvania to California. I was granted the opportunity to experience aging, afforded time to learn my passion of being a patient advocate, and discovered my love of public speaking, writing, and helping others. I've taken my struggles and firsthand experiences and channeled them into meaningful work that has helped educate and inspire countless people around the world. I've been able to soak in the simple pleasures of life that most let slip by.

To reach the peaks and triumphs of transplantation, one must traverse the valleys and endure some trauma. Healing is not linear, nor does it involve all physical wounds. There is the mental health journey as well. And it isn't just the recipient who is emotionally impacted; transplantation also affects the caregivers.

On numerous occasions, when someone learns I received a transplant, they say, "So, you're good now?" It's more than looking well and having stable lab numbers.

There are multiple transformative stages in the transplant journey that impact us emotionally, like receiving a new diagnosis, living in the trenches of an illness, undergoing dialysis and transplant evaluations, and experiencing guilt about needing support from a caregiver.

Leading up to transplant surgery involves anxiety surrounding waiting for "the call," enduring a big operation, healing from the procedure, juggling a career and family, and potentially experiencing grief if receiving a deceased organ.

Learning how to care for your gift of life involves taking daily medicine and enduring its side effects, undergoing regular lab work and doctor appointments, and learning the new way of living life with a suppressed immune system.

Adapting to a new normal requires navigating dating and relationships, considering having a

child, and experiencing stressors about the future like "how long will my organ last?" Recipients can feel guilty talking about anything but gratitude because they were lucky to receive a second chance at life. However, some go through a phase of "now what" because after being sick for so long, returning to good health and integrating back into society can be an adjustment.

I was a year and a half post-liver transplant in 2020 when the pandemic hit. For several years prior, my husband and I felt like our lives were on hold. The rest of the world carried on while we were navigating the transplant journey, from illness to post-transplant recovery. When the transplant fog was clearing, and we felt ready to integrate back into the world again—bam! COVID happened. I was the healthiest version of myself that I had been in years, and we've since had to isolate more than we ever have throughout any of my health issues.

Risk versus benefit has been a common equation with being a patient all of my life. It's been really difficult to take any risks and potentially jeopardize my stable health. My husband and I have felt more disconnected from society and struggle with feeling alone. It has been extremely hard to navigate COVID and feel the lack of empathy for those of us who are immunosuppressed.

I've been an avid patient advocate for 18 years. It helps give purpose to all I've endured and is very therapeutic. With the lack of information and support for the transplant community surrounding COVID, I had to find a way to help. I became a participant in an antibody research study to help discover the safety, efficacy, and durability of the COVID vaccine in transplant recipients. To partner with science and help our community at large has been such a bright light and positive effort to focus on during COVID. Through this study, I've learned the effectiveness of the vaccine personally, the impact of the vaccine in the transplant community as a whole, and I've received more valuable guidance from this study than anywhere else, which has helped our community navigate this really challenging time and me not feel as alone.

This lifelong voyage requires lifelong care and support. We can't expect to face death, survive, and

not be forever transformed. However, we have the choice about how we will channel our transformation and use it as our superpower.

Thanks to my two donors, no matter what is going on in the world or with me health-wise, I've learned that the *quality* of life outweighs the *quantity* of it. My unique vantage point of life, being grounded in gratitude, my will to survive, desire to live a fulfilling life, empathy, and passion for helping others are some of my transplant superpowers. I have been afforded the ability to see and experience life in a way only someone who has faced death twice and survived could, and for that, I am grateful because it has made life so much richer.

In the Fall of 2021, I spent several weeks alone in our RV. My health hasn't been well enough for years to consider doing an adventure like this. Through the fears, anxieties, and what-ifs of being 6.5 hours from my husband and home, it was a freeing and liberating experience of independence. After needing to be close to caregivers and healthcare facilities for years, this was an important time of growth, celebration of restored health, and example that what we've endured doesn't limit what we can do moving forward. I needed the reminder that I'm ok and that even if something would have come up, that I would have figured it out and still been ok.

The RV adventure and Northern California coast taught me of my love of pelicans, seals, and the treasures of the sea that appear during low tide. I learned the difference between being alone and solitude. I weathered a wild storm in the RV and was gifted with the views of 25-foot waves the following day. I was able to safely communicate with people outside at the campground for the first time since COVID and realized how much I missed making new friends, looking people in the eyes, and talking with them face-to-face.

As I stood on the bench at the top of the cliff with my arms wide open on the last day of my solo trip, immersed in appreciating the stunning rainbow and extraordinary life before me, I suddenly heard a loud swooshing sound. I looked to my right, and a blue heron flew right in front of the rainbow and my field of vision. The universe was wrapping me

with such surreal beauty that it felt like what only dreams are made of.

I was standing healthy and strong on the summit of the cliff overlooking a beautiful blue sea, with no intimidating mountain ahead to climb. I could feel the energy of gratitude throughout my entire body. My younger self could have never dreamed how those mountainous health challenges would transform her into the woman I am proud to be today. That moment and this journey carry so much meaning because of the road I've traveled to still be alive today, but what felt equally amazing was the hope I felt in that moment and feel today for my future and what lies ahead.



## The Courage To Live

Antonella Colace

**I** am not the patient. I have not received an organ. I am her mother; I am a shadow patient. My responsibility was to make decisions about a gift for my one-year-old daughter in the summer of 2007. A liver.

Elisa had a hepatoblastoma. After chemotherapy, the tumor might have been removed, but in the final stages of the work-up a portal vein malformation necessitated a transplant. The medical team at a hospital in northern Italy informed us of the intervention.

So many words! Trying to understand what they were saying seemed like a lost cause to me, but I quickly realized that these were people I should trust blindly.

These medical team members, by the end of the experience, would all become part of my family. They embraced us in their capacity as professionals and as human beings. I never felt alone or excluded.

How many times late in the evening I heard a soft knock at the door of Elisa's hospital room and behind that delicate touch, I found her doctor ready to leave for home, but not before one last



recommendation for his little patient and a wish of peaceful sleep.

The relationship between health workers and the family has developed into an effective relationship of communion and understanding, which has often translated into affectionate terms in communicating with each other. They asked me: “Mom, how is Elisa?”. . . . Yes—mom!

These highly trained medical experts have understood that a parent can sometimes somehow discern the danger behind the otherwise asymptomatic daughter’s subdued attitude; or a surreptitiously high fever, of little concern because Elisa was playing and laughing.

I was made to feel an active part of every initiative and decision. My observation point on Elisa, who could not speak for herself, was fundamental for them.

I never experienced the hospital as a hostile environment—quite the contrary!

It comforted me to have people around us, ready to intervene, reason, and solve the physiological difficulties of my little girl. The hospital was a room in my house, a room whose door was always ajar and in need, I crossed its threshold full of trust, hope, and courage.

Today some of those doctors and nurses are my friends. I have a lot of respect for them, gratitude, and admiration.

Elisa being placed on the transplant list and waiting for a donor were the first obstacles to overcome.

The “warrior” fought against two monsters, time and the tumor. The timing was everything because Elisa had to be in the period of non-toxicity after chemotherapy but could not wait too many weeks without active therapy in favor of a cancer that, lurking like a vulture, was only waiting for the ideal moment to start growing again.

The most dramatic thing to overcome and accept was hoping for someone’s death. For Elisa to live, someone else had to die. I felt like an executioner. I didn’t think of anything else; I didn’t sleep at night.

In the end, choosing to visualize death as a gift, I had to accept it.

It was summer, on August 20<sup>th</sup>, and another hot and boring night in hospital awaited us. The nurse came into the room to tell me that our lottery ticket

had won that night. There was a compatible liver for Elisa. The organ would come from a young woman who had died while swimming in the Sicilian Sea.

If they had stabbed me at that moment, maybe not a drop of blood would have left my body. I was paralyzed, incredulous, terrified.

My daughter had already been operated on, but it would be different this time. This time they would open her abdomen to remove her diseased liver and replace it with that of a dead young woman, by now sealed in a body bag in a Sicilian morgue. A cold body, deaf now, silent!

A young woman for whom, while I was rejoicing, some other shadow patient was despairing, caught up in an unstoppable whirlwind of pain.

I felt like throwing up while I cried tears of joyful hope. Guilt grew in my heart—we were thieves. Her misfortune and the pain of her family had become for Elisa and for our family the occasion of rebirth.

Wonderful and awful at the same time. A miracle and a tragedy.

At one point I would cross paths with her parents. They would find me via a social network. While organ donations are usually anonymous, Italy is a small country. Her parents were able to trace me as they followed the destination of those life diamonds that belonged to their beloved daughter. I felt like a child caught with a spoon of Nutella in her hand—or as Americans would say, with her hand in the cookie jar. But no. These were persons of great decorum, their pain restrained by an immense faith and even greater generosity. They simply wanted to be reassured that we would take care of the life that had been lost to them. I admit it increased my anxiety about the responsibility that accompanies receiving such a valuable gift; but in truth, I will always be grateful to them for looking for Elisa, the recipient of that portion of the liver so precious to them. Hearing their story and recognizing their excruciating pain allowed me to welcome their sacrifice with greater awareness and appreciation.

That unsuspecting young woman, who died on a happy afternoon at the beach, gave my daughter Elisa the gift of a possible future to live, and me the gift of a future to share with her.

I, the shadow patient, was the guardian of their gift. Elisa was certainly worthy of the gift, but was

I? In the end, though, selfishness prevails (is it even possible for one to be selfish regarding one's child?); worthy or not, refusal of such a gift was not an option.

The road would be long, very demanding; setbacks would follow the transplant. I was the guardian of my daughter's health and of a precious gift to be protected. Fatigue and fear would find no quarter. Every pain Elisa suffered has carved my soul. I felt it on my skin. In the expression on her face, I saw the pain.

My flesh suffered with her

I faced her homecoming with great trepidation. Every parent has had at least once in their life to get up during the night to check their child's breathing. I did this every night for the rest of her life, sometimes several times a night.

But I would learn to cherish the out-of-hospital time we shared. There would be too little of it.

Lost sleep due to long hospital stays. The continuous back and forth of nurses marching down the corridors first to a room for therapy, then to help a patient, and again to perform blood samples. The television is constantly on to make the loneliness in the hospital room less sad. Breakfast served too early, lunch when a late morning coffee would have been nice, dinner when you wanted a snack.

Over time, I became my daughter's personal nurse. In the hospital (it's different in Italy) and out, almost at the expense of our mother-daughter relationship. I had to learn how to dose medicines, and respect clinical schedules and rituals. Sterile cap and gloves, heparin and syringe, sterile saline, and disinfectant.

At home, I managed Elisa's central venous catheter.

I checked her blood pressure, oxygen saturation, kept track of I's and O's (intakes and outtakes). Did she poop or not?

For almost all her life, I observed Elisa with a clinical eye. I just missed being her mom and I still suffer from it today. I owe it to the unexpected conception of my second child, Tommaso, if at some point I was rehabilitated towards a more maternal attitude. He saved us both. He is a witness to those years. Even as a toddler, he came to visit us in the hospital. In Italy, when children are

ill, the whole family participates in the emotional effort necessary to care for them, including small siblings. He, my parents, the doctors, the health workers were all points of support when my heart needed a rest.

In retrospect, it was much more challenging than I had imagined. Above all, being aware that I could not forget anything was a great burden to carry. Elisa was linked throughout her life to taking a drug that prevented her body from rejecting the received liver. Nature does not understand the heroic act of human intervention on the unfortunate fate of an unfortunate living being.

The doctors had performed a miracle by replacing the non-functioning part of the gear, but to perform the magic fully, my daughter had to take immunosuppressants, which reduced her body's defense system. It was like killing her anyway! I thought this for a long time.

I had learned so well to manage periods of great difficulty. Paradoxically when we went through more serene seasons, I felt like a tortoise without a shell. I was more afraid of the stillness than of the storm because, in truth, I had learned to swim with energy in the storm; the stillness made me suspicious and restless. Elisa and I floated in the water with a donut in a deep, black, horizonless sea until 2017.

What happened still affects my life today. One color, jaundice yellow, reminds me of the ward walls in the hospital; a smell—that of disinfectant—when I sense it I am suddenly in the dressing room; a sound, Elisa is playing with her beloved doorbells . . . When I bought the new car, the first time behind the wheel, I suddenly felt a strong discomfort. I didn't understand why, but I was sick! It happened over and over . . . then suddenly everything was clear. Whenever I put the car into reverse, the beeping of contact with the vehicle behind me brought me back to the ICU. The same bell sound! The same thing happened if I got too close to the car in front of me.

It happens like this. Do not forget.

Perhaps everything is a bit covered up, but it is the life I had and that accompanies my present.

I understand one thing though—organ donors are not deaf or silent. The act of donating an organ

restores voice to the innocent and comfort to those who lose a loved one. The act of donating an organ offers life after death in a carousel of solidarity towards the human being.

Science, human love, that incredible gift, the courage and commitment of all the protagonists of my story allowed me to enjoy the presence of my daughter for 11 years. Elisa's journey was devastating but at the same time it was the most incredible and rewarding experience of my life. We miss her, but she is with us every day, in our trust in others and in our desire to take care of those in need.

We have learned a lot!

Thank you, my love.



### **My Gratifying Testimonial of My Extended Warranties of Life**

Danette Ragin

**M**y name is Danette Ragin. I am a 2-time kidney recipient who has been diagnosed with ESRD (End Stage Renal Disease). Both transplants were performed in Baltimore, Maryland. I am also a 3-time Donor Family Member and the proud Mom of a living donor.

I received the first kidney from a deceased donor on June 22, 2008. The donor was traveling thru Maryland with her family on vacation and experienced heart complications. My second kidney was donated to me by my youngest daughter Angel on December 20, 2016. I am thankful to God for both of my extended warranties. I'd like to share a little about my journey with you.

Around the year 2002, I started seeing my PCP (Primary Care Physician) for terrible migraine headaches, which on occasions lasted for weeks. After several tests, she expressed her concerns. I had been spilling protein in my urine and my kidney function was showing some abnormalities. My PCP sent me to see a neurologist after several failed attempts to gain some type of reprieve from the nerve-racking headaches. My nephrologist

confirmed my PCP's diagnosis, and I had visits with the nephrologist every 6 months until they noticed a substantial change.

"Ah, Mrs. Ragin, you're in the beginning stage of End Stage Renal Disease". Boom! (That hit me like a ton of bricks.) "Umm, you mean I have kidney failure! No! Not me. I've worked in dialysis. That can't happen to me!"

Of course, I was in complete denial. Both my PCP and nephrologist were very supportive mentally, physically, emotionally, and even spiritually. This information was so devastatingly painful that I started working harder and longer. I turned into a Superwoman with my family, work, and church. I was trying to drown out the fact that my health was being compromised, refusing to believe this could happen to me. I started to slow down in my daily functions, my appetite decreased, and I lost weight as a result. I thought that my weight loss was bringing my "Sexy Back," only to realize that I am not exempt from sickness. My nephrologist assured me of a possible solution. He advised me to have my name placed on the waitlist of one of the transplant centers in Maryland.

In October 2006, I had surgery to have an A/V fistula placed in my left arm to prepare for possible dialysis treatments in the future. In January 2007, I went to be evaluated for a kidney transplant. I was given 6 weeks to complete all required tests to secure a place on the transplant waiting list. Determination allowed me to complete all tests within 2 weeks.

In April 2007, I was approved to be placed on the transplant list. In October, I had a PDC (Peritoneal Dialysis Catheter) placed in my abdomen so that I could dialyze myself at home. I loved it but it didn't love me. It was removed in January 2008. Right afterward, I received my first unsuccessful call to be transplanted. (The kidneys were cystic and could not be used.) "Bummer." I also received another call in April 2008 (Easter Sunday). Those kidneys were at another hospital in Maryland, so if the waiting patient at their facility refused the kidney, I would be next in line. The patient accepted the donation. It wasn't my turn yet.

In the meantime, I had already started hemodialysis in mid-March 2008. On Saturday, June 21,

2008, while enjoying the weekend with my family, I received a call around 2:30 p.m. My youngest daughter and I were out shopping. We were in a crowded store that was going out of business, and I felt my phone vibrate. I noticed a slightly familiar number. I stepped out of the store to retrieve the call.

“Mrs Ragin . . .

Me: Yes.

“Danette Ragin . . .

Me: Yes.

“We are calling from the University with an organ offer for you!”

I told them they had me at the sight of the first few digits of the phone number they were calling from!

In June of 2016, I was advised that my kidney function rate was bordering just above 20%. Upon returning from the 2016 Transplant Games of America, it was confirmed that my function had dropped below 20%, and I was placed back on the transplant list. I shared the heartbreaking news with my family.

Two of my daughters, along with one of my Godsons, volunteered to be tested. Amazingly all 3 matched. Can you imagine my excitement? Since only one person could be worked up at a time, I had to make a choice. They all had been newly married, although two of them had newborns. My youngest daughter was adamant about being the one to be worked up first and was the closest match. Our surgery was on December 20, 2016. She is doing amazingly well and, since then, has given birth to two handsome sons.

This transplant journey has had its ups and downs, although I would not recant a moment of it. I truly believe that the Lord’s direction for my life has significant reasoning. What reason? I don’t know, but I am going to keep going until the Lord says, “enough!”

Since my transplant, I have actively participated in the following affiliations:

- Donate Life Ambassador
- Living Legacy of Maryland Volunteer
- Living Legacy Foundation Ethics Committee Member
- Living Legacy Faith Base Community Outreach Member

- Transplant Games of America—Team Captain for Maryland
- TRIO Member (Transplant Recipient International Organization)
- VTA Member (Veteran’s Transplantation Association)

If it’s positive and regarding transplantation, count me in!

I would like to encourage anyone who has received any type of transplant (or family members of people who have received a transplant and would like to be involved by giving back) to seek out your local Donate Life Chapter and volunteer. Opportunities will start to present themselves to you and the rewarding feeling is astronomical.

Also, if you’d like to register to become an Organ, Eye, and Tissue Donor, you may do so by registering at your local MVA or at [www.donatelife.org](http://www.donatelife.org). Once you’ve made your decision, please be sure to have a discussion with your family members, enlightening them of your wishes.



## Blessed Beyond Measure

Barbara Bischoff

**A**staph infection and a stranger saved my life. I was in a freak accident that resulted in an emergency splenectomy. During my recovery from the accident, I developed the staph infection, which required my doctors to run additional tests. It was then that I was diagnosed with liver cancer. I was terrified and my first thought was I am going to die. I didn’t share my diagnosis with anyone. I don’t know if it was fear or denial but after following up with my doctor and scheduling an appointment for transplant evaluation at Johns Hopkins, it was all too real to keep it a secret. I knew I couldn’t do it alone, and I needed my family.

My transplant evaluation was on June 22, 2015, which was my 45<sup>th</sup> birthday. After meeting with the transplant team and listening to their every word, I began to feel hopeful that I could do this, which was

probably the best birthday gift I've ever received. Ten months later, I received my new liver, and I'm grateful every single day for the gift of life.

Although I didn't wait long, it wasn't easy, and it was a very emotional time. I felt sorry for myself because I couldn't get out of bed most days due to the fatigue. Yet, at the same time, I felt guilty because I was impatiently waiting for someone to die. I leaned on my loved ones and the transplant team.

I got the call one night at 2 AM. A liver was available. It was time! We were very emotional, waiting for confirmation of the surgery. We said prayers for my donor and their family. We addressed the possibility of death but didn't waste too much time on it. I was ready for my surgery and had confidence in my doctors and faith that I would be just fine. After finding out the liver was good and the surgery was a go, I was wheeled into the operating room where many doctors and nurses were preparing. I couldn't believe how calm I was feeling. I knew they had me.

I awoke after a twelve-hour surgery feeling a million times better. I was surprised by how great I felt. My recovery was going as smoothly as it possibly could, but I was still struggling with guilt over my donor. During a conversation about it with one of my nurses, she said, "Your donor didn't die so you could live. You're alive because they died." Those words resonated within me, and I was able to focus on the overwhelming gratitude I was feeling. After about a month of residing and recovering in the hospital, where the care was top-notch, I was discharged to continue recovering at home. After a few days, I started experiencing some setbacks and ended up back in the hospital due to rejection. I was a resident again, but the nurses were so kind and compassionate. I knew I was where I needed to be. Luckily it was mild and handled with strong antibiotics. I was back home after a couple of weeks. I believe my recovery went so well because of the doctors, nurses, and my family's support. The quality of care I received is beyond reproach, and I believe that has made everything that much easier for me.

Life is a blessing, but every day is not perfect. Almost six years after the transplant, everything is going great, but I now struggle with severe

migraines. I look at it as a small price to pay for being alive and being able to enjoy the good days. My first grandson was born the same year I had my transplant. I am here to spend quality time with him. That was one of my biggest concerns while I was waiting. Was I going to be here to meet him? Was I going to be able to be there for my daughter? Was I going to be healthy enough to enjoy playing with him? The answer to all these questions is yes. I have been given the gift of life, and I'm so grateful.

During my recovery time in the hospital, volunteers who were recipients themselves would visit to give support and share their stories. It was inspiring. I knew that when I recovered, I wanted to help others in their transplant journey. Today I am a volunteer. My wish is that my story gives someone the strength and hope so graciously shared with me. The organization that I volunteer for is made up of donor family members, living donors, and recipients. I haven't been successful in communicating with my donor's family; however, I believe writing the letter to the family has been therapeutic and healing for me. I'm so grateful to be able to thank donor family members that I've met through volunteering. The loss of a loved one is a great tragedy but saving a life is a grace most of us will never know. I only hope that donor families are able to find some comfort in the gift, the blessing, and the second chance their loved one has given to a stranger.



### **Lemons to Lemonade**

Cindy Conrad, Mike Conrad, Katie Johnston,  
Crit Conrad & Doug Hanto

Cindy

**T**urning sideways, I studied my reflection in the full-length mirror, admiring the miracle of my 36-week pregnancy. Touching my protruding tummy, so full of life, I smiled, finding myself grateful to be pregnant in the 20<sup>th</sup> century



when safe pregnancies are commonplace . . . the norm. But not this time . . . .

Monday, December 7<sup>th</sup>, 1987: Hospital's Sibling Class. I didn't feel well (maybe the flu my husband, Mike, had?), but I was determined to attend for the sake of our 3-year-old daughter, Katie. This was an important part of her understanding soon she'd welcome home her baby brother, Crit. I came home exhausted when the phone rang:

"How did everything go?" my husband inquired. "It was rough," I breathlessly replied, "but I did it!"

Red flags immediately went up, triggering action on Mike's behalf. "This isn't right," he objected. "I'm calling the doctor back." . . . our third and final call to the doctor that day. Mike insisted they admit me, so back to the hospital we went.

Tuesday and Wednesday, Dec. 8<sup>th</sup> & 9<sup>th</sup>: a myriad of doctors would come and go, asking liver-related questions: "Have you been out of the country lately? Have you had any raw fish?"

Wednesday evening, December 9<sup>th</sup>: I struggle to make my way back into bed having used the restroom. The next thing I remember, the bed was wet with brown, stained water. Had my water broken? Much like an out of body experience, I watched as my finger pressed the nurses' call button . . . and I was gone.

## Mike

When I arrived home on Monday, Cindy looked awful. She could barely catch her breath and walking was difficult. I rushed her to the E.R. A stat blood test revealed the possibility of HELLP<sup>3</sup> Syndrome. By Wednesday, my mind was reeling when I was told she needed an emergency C-section. As they wheeled her off, I kissed her and held her hand. I had no idea what was to come. Our (healthy!) son, Crit, was born the following morning, December 10<sup>th</sup>, and immediately whisked away to Pediatric Intensive Care. Cindy was sent to Intensive Care; it was doubtful to me

<sup>3</sup> HELLP (Hemolysis, Elevated Liver enzymes and Low Platelets) syndrome is a life-threatening pregnancy complication usually considered to be a variant of preeclampsia.

that she would survive. I made calls to family and friends—both sets of parents arranged to fly in to say their final good byes.

Friday, Dec. 11<sup>th</sup>: Due to developing multiple organ failure and worsening disseminated intravascular coagulation, Cindy was transferred to another hospital in the area for further evaluation.

## Dr. Doug Hanto

I can still remember the discussions in the intensive care unit about Cindy's rapidly deteriorating condition and the decision to list her for an emergency liver transplant for fulminant liver failure caused by acute fatty liver of pregnancy (AFLP). There was added urgency and emotion because she was young and had just delivered a healthy son (two days prior), who needed his mom. In addition, Cindy had a husband and daughter that loved and also needed her. We were confident Cindy was not going to get better without a liver transplant, but would a donor liver become available in time? Fortunately, in the face of tragedy, another family made the selfless decision to allow organ donation from someone they loved and lost. We were able to successfully transplant Cindy two days after her hospital transfer. Cindy was the first patient reported who underwent a successful transplant for AFLP with her case report published in the journal *Hepatology*.

## Cindy

My remembrances during the transplant:

- Hearing someone say, "We have a liver," and wondering why they were telling me this.
- Walking through a crowded living room, out a sliding glass door onto a dock, to await boarding a boat.
- Going through a bright tunnel.
- Waiting backstage in a large venue to candidly speak about the miracle of my transplant.
- An enveloping and permeating sense of God's peace and love surpassing my understanding.
- A glorious sense of Christmas angels rejoicing over Christ's birth, and humbled by their joyous rejoicing of *our* son, as well.



## Mike

Cindy was put at the top of the national list for a donor liver. By the grace of God and the thoughtful decision by the donor family, she received the liver of a critically injured adolescent. Her transplant began late in the evening on December 12<sup>th</sup> and concluded about 12 hours later on December 13<sup>th</sup>. Despite some preservation damage, her liver began producing bile immediately.

## Dr. Doug Hanto

I remember the special moments when:

- We told Mike we had been offered a liver for Cindy (I'm sure he jumped up and down).
- We told Mike the transplant went well.
- We saw Cindy wake-up and recognize Mike at her bedside.
- Cindy saw her son for the first time.
- She went home 26 days after her transplant.

The rewards of being a liver transplant surgeon don't get any better than that. I was privileged to be part of an outstanding team that made Cindy's transplant possible and successful.

## Cindy

December 16<sup>th</sup>, 1987 (a week after losing consciousness): I gradually opened my eyes, taking in the sights and sounds of an ICU isolation room. What *happened!* Masked doctors surrounded my bed, all eyes on me. A doctor to my left, holding my hand was the first to speak. "Do you know where you are?" he inquired.

"Yes", I confidently, yet incorrectly replied, not thinking he'd push the issue.

"Where?" he pushed. I hesitated. For some unknown reason, I thought the hospital's name had something to do with a farm. All I could think of was. . . birds.

I guessed and uttered the name of another hospital in town, forgetting that it was a children's hospital . . . not an option.

He gently corrected me, relaying where I was and explaining, "You've had a baby boy and a liver transplant."

Wow! I didn't even know that was a *thing!*

## Mike

I could write a book about the ups and downs over the next 4 months and the emotional toll it took, and we will *never* forget the sacrifice the donor family made to save so many lives that day! Through this experience, family, friends, our church family and the cardiology medical community that I worked with were forever changed. Liver transplantation was in its infancy in 1987, and there wasn't a day, week or month that went by when someone wouldn't ask about Cindy. People *still* ask today, almost 35 years later! A true miracle occurred that December 13<sup>th</sup>, 1987 and I am grateful to God for putting us through this, as it has only made us stronger and given us a deeper appreciation of life.

## Katie

### *Childhood*

Growing up, my impressions of my mom's transplant were pretty vague. Most of my memories were from stories retold to me, or from re-watching the news segments that featured her story. The details that I *do* recall firsthand are typical of a three-year-old: lots of time playing with Grandpa; visiting my mom in the hospital; discovering a big piece of lint in my pocket; and an overwrought, devastated daddy crying, "Mommy might die," to which I replied, "Well, I guess we'll just have to throw her pillow away!" Kidding aside, I *do* know that I always felt loved, safe, and cared for, and I don't remember ever being scared.

### *Adolescence*

Somewhere around third grade I became conscious of the fact that my mom's transplant story was actually quite miraculous. Nobody else I knew had a parent who had undergone a transplant, and the ways that she retold her story became impactful to me. My mom was asked to speak at our schools, provide stories for print and TV to celebrate milestone years post-op, and it always made me proud to be able to celebrate her life.

This was also about the time that I realized the toll that the transplant, medications, and subsequent hepatitis C (from blood transfusions during surgery) took on her. I watched her organize pills, suffer through exhaustion from Interferon, and try to rest when she could amidst her commitments to keeping our household afloat.

Through it all, she absolutely sought to make the most of her second lease on life. She volunteered with several organizations, took us on incredible trips around the world, and gifted us with her presence in a very intentional way.

#### Now

The story of how my mom's transplant is woven together with my *own* acute fatty liver of pregnancy diagnosis after the birth of our son, Ansel, is one that I'll never tire of telling! My mom and I were both given double gifts of life as a result of this disease. She was granted the miracle of her own life and that of her healthy baby boy. After determining that it wasn't safe for me to get pregnant again, my husband and I sought to adopt and were matched with twins. Two gifts of life, two times over, 32 years apart!

The miracles of life and medicine have intersected so '*Acutely*' (see what I did there?) with our family, and I just can't bring myself to use the word "coincidence" when it comes to re-telling our stories.

#### Crit

I would say that ultimately, the liver transplant itself hasn't affected me all that much. What *has* had a direct impact on my life, is the outcome of the transplant. First off, without the transplant, I wouldn't have grown up with a mother! Having such a loving, caring, and fun mom in my formative years has shaped me to be the person I am today. And without the liver transplant, she wouldn't have been there for that. I doubt I would have that passion for outdoor adventure, spur of the moment trips, musical instruments, and countless other things!

The transplant has also given me new perspective on being an organ donor. Without my mom

going through that experience, I doubt I would be as adamant about being an organ donor myself. It gave me a mom so, if an unfortunate incident ever arose, why wouldn't I want to provide the same for another family?

The transplant has given me many opportunities to connect with other people and families that have experienced the life-saving effects of a transplant. My girlfriend, Molly and I even talked about it on our first date!

Reflecting on when my mom went on Interferon and seeing how exhausted she was throughout that process instilled in me a mindset that even a great amount of pain and suffering can be temporary and you can persevere through that in pursuit of a better outcome on the other side.

#### Dr. Doug Hanto

It's been a joy to maintain a friendship with Cindy and Mike over these past 34 years and to witness the growing up of her son, Crit, and daughter, Katie, through pictures. Cindy and Mike are filled with joy, seek and enjoy adventures together, and are devoted to their family, never seemingly impeded by an unexpected event that changed their lives 34 years ago. And Cindy herself—she is a force of nature who has lived life to the fullest as a mother, wife, friend, and now grandmother, never slowed or intimidated by events of the past, but looking forward to every new day as an opportunity to bring a little joy into someone else's life.

#### Cindy

Now, almost 35 years later, I continue to learn to grow in faith and to treasure others and life. Sorrow has been turned into joy. Our hardship has become our delight, for God has taught us to make lemonade from life's lemons. He's changed my priorities, increased my perspective and continues to prepare me for this world and the world to come, all thanks to my donor and his family, Dr. Hanto's amazing team and the entire caring staff at the hospital where I received my transplant! In retrospect, if given the choice between my former

life or life as it is today *with* a transplant? . . . Hands down, I would gladly choose the latter! Now let's go get some lemonade!



## How Do You Decide Who Saves Your Child's Life?

Meghan C. Halley

I received the call that my son would be listed for liver transplant the day after I found out I was pregnant with my third child. It was not the call I had been hoping for, though by that point in his journey, I should have expected the unexpected.

My son wasn't even three at the time, and he had already been diagnosed with multiple abnormalities in his intestines in addition to the biliary atresia that had led us to liver transplant. He had endured four major abdominal surgeries and many subsequent complications. The year before, out of the blue, he had suffered a major stroke and was still learning how to walk for the second time in his short life. His many rare medical issues led his physicians to refer him to the Undiagnosed Diseases Network to try to find a unifying diagnosis that might help them understand the underlying mechanisms causing all of his problems.

It was after all of this that we got the call that it was time to plan for transplant. At that point, he had suffered multiple bouts of cholangitis through the course of his many other hospitalizations, and his liver was not in great shape. However, his liver was only one consideration. His transplant team was worried about how his other complex medical issues—and their lack of understanding of their underlying mechanisms—would affect his ability to wait for a cadaveric donor. As they explained to us in terrifying detail, most kids have to wait until they are incredibly sick to qualify for a cadaveric donor liver. Some die waiting. They were worried that my little boy would be among them given his other issues. They wanted us to explore living donation as soon as possible.

But who would be the donor? I was immediately ruled out as a candidate due to my pregnancy and blood type, but my husband was potentially a match. We were still processing this news with equal parts relief and trepidation when we received a call from my sister. "I checked my blood type, and I'm a match. Please let me do this for you," she said.

I didn't know how to respond. My husband was initially adamant that it was his responsibility as the father to be the one, and I understood his instinct. If I had been eligible, I would have felt the same. The risks of being a donor felt too big for anyone else to accept. I would feel terrible if my sister had even a small complication. What if there were longer-term consequences or even the ultimate consequence? Outcomes for living donors were somewhat reassuring, but it was a major surgery with multiple potential risks, from major bleeding and other surgical complications to long-term challenges, including abdominal pain and depression. Though rare, there had been cases of donor death. I couldn't live with myself if something happened to her.

On the other hand, the idea of my husband donating also was terrifying. I would almost certainly still be pregnant when the transplant happened, and we also had another child who was just four herself. We lived in California, far from any family. We didn't have much childcare—or extra money to pay for it—since I was not working outside the home at the time. Even if all went perfectly, my husband would not be allowed to lift more than 10 pounds for at least six weeks, during a time when I would likely be in my final months of pregnancy. And what if there were complications? How would I care for our three children on my own for an extended time, or even forever? The thought was incomprehensible.

Then there was the fact that my sister, who was offering this generous gift to my son, was herself a recovering alcoholic. She had been in recovery for over five years at the time, which meant that she did meet eligibility criteria, but I was worried about the mental health risks. The doctors told us that rates of depression were as high as thirty percent in living donors following surgery. Given the mental health challenges that had contributed to her alcohol use in the first place, I was worried

that she might be de-stabilized by the surgery and the subsequent physical challenges she was likely to face. On the other hand, she was well-supported in the sober community in her hometown. She had been managing her mental health challenges for most of her life and was stable on medication. She lived close to our other family who could support her. She had a stable job, good insurance, and ample medical leave. She didn't have children of her own.

Ultimately it was my sister who convinced us. In contrast to our deep uncertainty, she was so sure. It seemed that giving this incredible gift to her nephew was part of how she was shaping her own narrative of recovery. Maybe it helped her feel like she was finally there. Should I really stand in her way? "Let me do this for you," she kept saying, and so we did.

Today my sister is married with a beautiful 2-year-old boy of her own and an incredible L-shaped scar on her abdomen that matches my son's. My son is seven and still struggles with many medical issues, but he also goes to first grade, loves playing with his sister and younger brother, and occasionally asks questions about his "piece of Auntie Lolo's belly" that make us smile.

Were we selfish to let my sister take my husband's place? Even as I write this, I still feel guilt creep up my neck. At the same time, though, even posing the question of whether we should have "let" her do it feels unfairly dismissive of my sister's active role in deciding to offer such a gift in the first place. Though my husband and I were technically in the driver's seat, I do believe it was a decision we made together. Our only choice now is to be grateful.



## Metaphors and the Transplant Experience

Madalina Meirosu

**F**ire and ice. I felt so cold. Every evening, I was shivering, and I had no idea why. I was just a kid, twelve years old, and shivering every

night before going to bed, even though it was warm in the house, even though we had plenty of warm blankets. I hated evenings because the cold was unbearable when the sun went down, and I had no way to escape it. It was emanating from my bones. I no longer mentioned it to the adults because the few times I had spoken of it, teeth chattering, I was just told to get under the blankets. Winter was coming from inside my bones, every evening, and I was freezing, and there was nothing I could do about it. And then, one evening, fire broke out inside my body. It was as if my body had had enough of winter and was conjuring up a volcano—the fever was so high that I was delirious, dreaming of fires and bombardments, and fighting on a battlefield where everything spelled doom.

It took doctors a long time to figure out what was wrong. Romania had barely emerged from a bloody revolution in 1990, overthrowing a dictatorial regime, and medical equipment and knowledge were limited. Doctors struggled to make sense of my symptoms and tests, and by the time I was diagnosed with obstructive nephropathy and renal failure a few months later, it was clear that there was nothing to be done for me, at least not in Romania. Or as a famous Romanian kidney specialist told my desperate parents, towering over my bed: there is nothing to be done other than find a burial spot. Cold, again, in my bones, day and night. And now the cold took on a different meaning—the prelude to the cold of an open grave in front of me.

My parents did not give up, they could not accept that their child would die so young, and a doctor in the capital city suggested that my situation would have been different had I been able to go abroad. Western Europe had the medical resources to treat me, but it was financially impossible for us to afford it. But my parents did not give up, and eventually, after numerous appeals, a miracle took place, and a teaching hospital abroad agreed to treat me. After a couple of surgeries, I gradually emerged from the winter within. I grew in height dramatically, put on weight, and began to thrive, though the occasional cold shivers in the evening reminded me what the doctors had said: the surgeries were a temporary patch. My remaining kidney had very limited

functionality and would give out sooner or later, thereby forcing me to be on dialysis or to have a kidney transplant.

Just before my 18<sup>th</sup> birthday, we began to prepare for the worst. The cold had returned in the evening, this time accompanied by nausea. I was asked if I would like to go ahead with the transplantation—I had been on the transplant list, and though nothing had come available, my father was a match—or if I preferred dialysis. I understood the benefits and advantages of both. I also understood that there would be more chances for a kidney from a post-mortem donation if I were on dialysis. I did not want my father to donate. There was shame and stigma in being chronically ill in Romanian culture, a shame that had been a constant reality for me. Especially in families with uneducated backgrounds, deeply steeped in a poor peasant mentality, being ill meant not being useful or worthy. Disability equaled shame. I did not want that for him. From what I understood, his health and ability could have been impacted after the donation. And I did not want that for me; I preferred to finish high school and deal with whatever health challenges I might have after finishing.

My doctors suggested that I reconsider—that it would be better for me to receive the transplant as soon as possible. But I stuck to my plan, and my parents went along with my decision. And the cold returned, a daily occurrence, accompanied by muscle pain and headaches, and my health began to worsen. Dialysis did not go well for me. I often felt like my bones were made out of sand, and that I was going to shatter, that my body would break apart in a confetti made of grains of sand, and I would disintegrate. I did not feel at home in my body, a body that was struggling to function. I was utterly exhausted, and my brain seemed to be slowing down. At times I imagined that the sand from my bones was slowly grinding against and blocking the intricate wheels of the mechanism of thought—considering my sensations with the help of metaphors was the only way I could make sense of my felt experience.

I was on dialysis for about a year and a half. By that time, the transplant became unavoidable and it was decided that my father would donate

to me. I was hovering on the edge of the grave yet again, an arctic chill emanating from the marrow of my bones. I was frozen. It felt like the cold from the grave had finally managed to creep out and penetrate me. I remember a day shortly before my transplant when I had a chance to sit in the Botanical Garden in Bucharest; it was warm, the middle of May, and everyone was wearing summer clothing except me. Wearing a warm long black dress with long sleeves, my long black hair floating around me, I sat on a bench surrounded by fragrant plants. The garden felt surreal—being outside seemed unreal because I had been confined to my home and hospital rooms for such a long time. The air was thick with floating poplar fuzz, unfettered and fairy-like, and it transformed the garden into a magical place. The quality of the late spring light, filtered through a multitude of tiny fluffy clouds, felt otherworldly and, all of a sudden, after a long hibernation, I felt so alive, and present, and grateful to be alive and to swirl around, a black fluff in a surround of white fluff. A dizzying mix of feelings: I was grateful that I could experience this moment before my surgery. I was aware that these might be my last moments outside, that I might die during the surgery because I was in very poor shape; but I was so happy, so very happy to be allowed to experience this miraculous garden. The winter in me seemed to relent for just a little bit, thawing under the late spring sun.

The first thing I noticed after my transplant was the fire that seemed to be coursing like molten lava through my veins. That, and the tubes sticking out of me. The fire, or rather the absence of the frozen cold, made me very giddy. I was on top of the world, I was twenty years old and I could think in terms of a future. I felt so utterly blessed and happy. Yes, yes, I knew that there was no guarantee that there would be no complications going forward, but I was happy, so very happy, simply happy to be alive. The fire in my veins continued, and doctors told me it might be the immunosuppressants, that it would take me some time to get used to them. I saw it as the fire of life making its way into my frozen body. I soon realized that I needed to relearn how to read my body, be in my body, and open myself to the new signals I was receiving.



My new kidney—my father’s kidney—never felt foreign. It always felt, from the beginning, that it was right where it belonged. As such, borders between bodies became fluid for me. The sense of living in a self-enclosed body was challenged by my new experience of living with a kidney that had functioned in another body but was now integral to my own. Also unusual were the ways in which my body was now reacting to heat and cold. Cold water from the tap burned me—it was similar to how cold water seems to burn your hand when your hands are frozen from sub-zero temperatures. Unlike my new kidney, my skin felt foreign, as if it belonged to someone else. I registered its sensations remotely, not in a detached way but as if I were distanced from the stimuli, as if I were experiencing them through an avatar, as if they were the sensation of a sensation that someone else’s membrane had felt and communicated to my brain. But through all of this, there was the fire. Fire was coursing through my veins, and I often felt like a phoenix being reborn from this fire.

I listened to my body, carefully, patiently, lovingly, trying to figure out a new baseline. Though I was being administered a normal dose of cyclosporine, I watched what transpired in my body when I took the medicine, and, once I began to correlate my symptoms with the results of blood tests, I came to realize that the burning fire, especially the burning in my feet and heels, was a sign that my cyclosporine levels were high. I spoke with my doctor about it, and though she was understandably resistant to bucking standard procedures concerning normal ranges of immunosuppressant medicine, she still listened to me, thankfully, and began to trust my insights into my own body. Slowly but surely, we reduced my cyclosporine to a minimal dose, with the result that my cyclosporine levels are now so low that doctors in the United States are always alarmed by my test results. However, because I have been on this dosage for more than twenty years, they dare not make changes to a regimen that has been working well for so long.

I still have a hard time thermoregulating. I overheat in the summer and feel extremely cold in the winter most of the time. Like a reptile, I absorb the temperature of my surroundings. Sometimes the

cold in my bones resurfaces for a short time, and I am flooded with anxiety. Sometimes my skin still feels remote, and sensations feel like the sensations of an avatar, transmitted to me, and I need to reprocess them.

I have now lived longer with my transplanted kidney than I have without it. I have done things that I had not been permitted even to imagine as a child, in part because of my background but also because of my health challenges. One of the unexpected directions that my life took led me to a doctorate in comparative literature, the study of which opened my eyes to the importance of metaphors in making sense of the human experience. During my illness, I instinctively had recourse to metaphors to make sense of my suffering. Fire and ice, the ice cold of the grave, and the fire of the transplant process have been defining motifs throughout my transplant experience.

I wish the creative use of metaphors could somehow reframe my relationship with my kidney so as to create a sense of ongoing closeness with my father, a feeling that he is still an immediate presence in my life. I wish I could say that I feel a tangible physical connection to my father, especially now, a little over a year after his death. I have read quite a few accounts of transplant patients feeling an ongoing connection with their deceased donors. And, given the close relationship that I had with my father, I would expect that, if in fact a donated organ can mediate the presence of the donor, I would be able to feel something. Curiously, I feel much more connected to my father when I am in Romania, wandering over the hills that he loved, touching the earth and looking at the sky. I am still here, mourning him, but I am also grateful for being alive, and looking forward to springtime.





## Commentary

# Patients Can Make Policy Narratives for Organ Donation and Transplantation

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**Abstract.** This commentary discusses 13 unique stories by patients who have received an organ transplant. Their stories are diverse and capture the essence of the highs and lows on the journey to needing, receiving, and living with an organ transplant. The stories speak to immeasurable gratitude, and all provide insight into how we might support more fair and equitable organ transplant system policies in the US and abroad. This commentary suggests that a narrative policy framework in organ transplantation can have a positive influence as we formulate, adopt, and implement transplant policy.

**Keywords.** Organ transplantation, Tissue and organ procurement, Bioethics, Narratives

## Introduction

Receiving an organ transplant provides significant benefits for many conditions that result in organ failure. Despite the pandemic, an increasing number of deceased and living donor transplants are being performed worldwide. In the US, the Organ Procurement and Transplantation Network reported 41,345 transplants were performed in 2021, up nearly 6% from 2020 (Lentine et al., 2022). Despite leaving recipients full of gratitude

for their life, made possible by donors through successful organ procurement and transplantation, the patient stories in this collection provide an opportunity to highlight systematic problems that exist. These narratives touch on some of them, including getting referred for a transplant, adding sick patients to waiting lists, and then keeping patients alive while they wait for the perfect organ.

The US Congress recently requested the National Institutes of Health study fairness, equity, and

transparency in the US transplant system. An Ad Hoc Committee of the National Academies of Science, Engineering, and Medicine (NASEM) studied the gaps, barriers, and opportunities for improving how we allocate and distribute donor organs in alignment with federal law (The National Organ Transplant Act). After a year-long consensus study, recommendations from the NASEM report were released in February of 2022. Even when policies are premised on all people being treated the same, health and other systematic disparities can undermine the public trust necessary for the organ donation and transplantation system to function. With an invigorated call to improve equity for justice, fairness, equity, and transparency, policy narratives from transplant patients can be of immense value in shaping public beliefs and attitudes about trust in the transplant system. In this commentary, I explore how a narrative policy framework approach, developed by Shanahan et al., can help with understanding the role of applying narratives to inform and support the organ donation and transplantation policy process (2018). With an invigorated call to improve equity for justice, fairness, equity, and transparency, policy narratives from transplant patients can be of immense value in shaping public beliefs and attitudes about trust in the transplant system.

### What Matters to Patients?

Patient stories can help question our existing definitions of what ‘success’ looks like in the field of organ donation and transplantation and shape policy discussions about what metrics matter. Currently, first-year patient and graft survival metrics are used for regulatory monitoring of transplant hospitals (Jay & Schold, 2017). Leilani Graham, a heart transplant recipient, writes eloquently about what other outcomes matter to patients and suggests the professional transplant community focus also on patient-centric goal setting. Graham writes, “Immediately after transplant, the team’s focus is purely on survival. Survive the 30 days post-surgery. Survive the year. Metrics, uncomfortably tied to transplant center success statistics and

funding, and clout have little to do with the patients themselves. What did I care to only survive a year? I wanted years. I wanted decades. It felt I wanted more than anyone was willing to pay attention to.”

Graham’s words speak directly to the NASEM recommendation to create a publicly available dashboard of standardized metrics to provide a complete human-centered picture of the patient-experience—from patient referral for transplant, time on the waiting list, and post-transplant quality of life (National Academies of Sciences, 2022). NASEM recommends that the dashboards be meaningful to donor families, individuals with chronic diseases and organ failure, for transplant candidates, wait list individuals, and their family members, to ensure accountability and partnership across components of the healthcare system. Policy narratives can help to develop these.

After being diagnosed with liver failure, Todd Frantzen candidly discusses how rare multiple organ transplants saved his life and that “my heart, liver, and kidney are all working fine right now” but Frantzen goes on to describe the crippling impact that the hospital stays and medications have left on his day-to-day life. The essay brings up questions about how transplant policy changes impact the way transplant hospitals and teams communicate with potential recipients about the transplant evaluation, status, and remaining steps, and speaks to the NASEM recommendation to ensure all persons with disabilities are represented in the transplant policy development process.

Ingrid Gould knew they would one day need a heart transplant but banked on future technology like 3-D printing being available by the time they needed it. Patients who need a new heart must be sick enough to qualify, and healthy enough to remain a candidate, survive the heart transplant surgery and then recover. In a view into a courageous journey through a heart transplant, Gould writes, “although clinically I was ready, I was not personally ready. I felt too good to trade an excellent quality of life for the promised miserable post-transplant year.”

What does success look like? For me, I want clinical trials in xenotransplantation (Montgomery

et al., 2022), more progress on genetic engineering, and mitigating the negative effects of immunosuppression on the body.

### **Organ Offers and Acceptance: What Do Patients Know About It?**

Many transplant patients describe the ups and downs of waiting in the context of “the call”—which is the call they await from their transplant hospital with news that a possible organ has been found that is a match for them. Priority for individuals on each organ wait list is based on formalized protocols, and organs are allocated on match-run algorithms. A patient’s access to an organ offer depends on the discretion given to the transplant team to accept or reject the organ for transplantation. Given this level of discretion, 20% of organs procured from deceased donors in the US go unused (Israni et al., 2021). As many of these unused organs that are procured could be used to save and heal lives, the NASEM report has challenged the transplant system to make it easier for transplant centers to say yes to organ offers and to increase transparency and accountability for organ order declines and prioritize patient engagement in decisions regarding organ offers.

In this series, James Moran puts this emotional experience into context and describes it as “characteristic of the cadaver [preference to use the term: *deceased*] transplant experience.” “You wait, you get excited, get let down, and then when you finally get the call, you’re cautiously optimistic.” “When the surgeon came, I asked him: “Is this the right kidney for me?” He replied with a smile: “Yes, it is.”

Can we be sure? NASEM recommendations call for transplant programs to document conversations of shared decision making that includes discussions of survival benefit relative to staying on the waiting list. Further, we can reduce the number of unused procured organs by requiring transplant centers to share the number and context of organ offer declines for a defined period of time (e.g., 3 or 6 months), which could improve shared decision making between patients, families, and healthcare teams.

### **Thanking the Organ Donor and the Family that Says “Yes.”**

Gratitude for the organ donor and their family is a common thread among all transplant recipients who receive the gift of life and is highlighted beautifully in this issue. Judith Ryan’s kidney transplant story brings to light that transplant patients may not have the words to express themselves. As a nurse, Ryan’s narrative encourages transplant nurses and social workers to actively assist recipients in understanding that it is never too late to say thank you to their donor. Christopher Lewis documents his trial of patience to receive two liver transplants, and now as a neuro ICU nurse, has turned personal passion into a profession that helps organ donor patients and their families. After receiving a kidney and liver transplant, a healthy and strong Valen Keefer explains, “I could feel the energy of gratitude throughout my entire body.” Allen Callaci writes, “I have not stopped thinking of my donor and their family in the years since returning home from [the hospital], although I only know minimal details about them.” Callaci continues, “I have reached out to the family with written expressions of my enduring and unending gratitude over the years through the proper channels but have yet to hear back. When I sent out my initial note to the family, I was told that the odds were that I would likely not hear back as it can be an overwhelming emotional experience for donor families to meet the recipient. This is more than understandable. My hope is only that my donor family found some small comfort and a sense of closure in my messages.”

Organ donor families are unique—they experience traumatic and sudden loss in tandem with the complex and life-changing process of organ donation. Some families of donors form close ties with the recipients of their loved ones’ organs, and others have no interest in communication after the donation, hence the sensitivity involved in these conversations and meetings. Correspondence between a transplant recipient and a donor family is coordinated through the transplant hospital and the organ procurement organization, and there may be different procedures for contacting donor families based on policies in place to protect the

privacy of both parties. Unless both sides agree to meet, correspondence is anonymous.

### **Conclusion: Developing a Narrative Policy Framework in Organ Donation and Transplantation**

Transplant patient narratives can be used to advance and contextualize policy recommendations and can elevate the voices of those facing disparities for more inclusion in the policymaking process. A basic policy narrative must have four elements, including the setting, characters, plot, and moral. The setting must relate to a policymaking context and may include institutional and socio-economic factors. Each story must contain a least one actor, who can serve as a hero or villain, and common story plots include the characters going on a journey, facing, and overcoming adversity, often relating to villains causing trouble and victims suffering tragedy. The moral of the story will be a take-home point that describes the cause of, and solution to, the policy problem. For policy narratives to be effective, they should help the audience imagine a concrete (rather than abstract) problem. The complex and gracious lives lived by transplant patients make this an easy task to accomplish if we are willing to listen.

### **References**

- Israni, A. K., Zaun, D., Rosendale, J. D., Schaffhausen, C., McKinney, W., & Snyder, J. J. (2021). OPTN/SRTR 2019 annual data report: Deceased organ donors. *American Journal of Transplantation*, 21 Suppl 2, 567-604. <https://doi.org/https://doi.org/10.1111/ajt.16491>
- Jay, C., & Schold, J. D. (2017). Measuring transplant center performance: The goals are not controversial but the methods and consequences can be. *Current Transplantation Reports*, 4(1), 52-58. <https://doi.org/10.1007/s40472-017-0138-9>
- Lentine, K. L., Smith, J. M., Hart, A., Miller, J., Skeans, M. A., Larkin, L., Robinson, A., Gauntt, K., Israni, A. K., Hirose, R., & Snyder, J. J. (2022). OPTN/SRTR 2020 annual data report: Kidney. *American Journal of Transplantation*, 22 Suppl 2, 21-136. <https://doi.org/https://doi.org/10.1111/ajt.16982>
- Montgomery, R. A., Stern, J. M., Lonze, B. E., Tatapudi, V. S., Mangiola, M., Wu, M., Weldon, E., Lawson, N., Deterville, C., Dieter, R. A., Sullivan, B., Boulton, G., Parent, B., Piper, G., Sommer, P., Cawthon, S., Duggan, E., Ayares, D., Dandro, A., . . . Stewart, Z. A. (2022). Results of two cases of pig-to-human kidney xenotransplantation. *New England Journal of Medicine*, 386(20), 1889-1898. <https://doi.org/10.1056/NEJMoa2120238>
- National Academies of Sciences, Engineering, and Medicine. (2022). *Realizing the promise of equity in the organ transplantation system*. <https://doi.org/https://doi.org/10.17226/26364>
- Shanahan, E. A., Jones, M. D., Mcbeth, M. K., & Radaelli, C. M. (2018). The narrative policy framework. In C. M. Weible & P. A. Sabatier (Eds.), *Theories of the policy process* (4th ed., pp. 173-213). Routledge.

## Commentary

# Transplant: A Second Chance at Life

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**Abstract.** This commentary discusses thirteen stories written by transplant recipients or caregivers and describes what they experienced during their transplant journeys. The stories explain the importance of support during transplant from both family and loved ones as well as the medical team. The authors describe challenges they faced when medical teams were not supportive and, in their stories, refer to transplant as a journey filled with positives and negatives, an experience that never ends. What is most interesting about these stories is the deep connection the recipients and caregivers have with their donors. These connections are filled with mixed emotions of gratitude, guilt, gratefulness, and a sense of responsibility to protect the gift they received.

**Keywords.** Transplant recipients, Organ donors, Caregivers, Support, Emotions, Guilt, Narratives, Bioethics

Transplant is defined as taking an organ from one person and putting it into someone else (Oxford English Dictionary, 2022). While this may be a simple and straightforward definition of the term, a transplant is anything but simple. It is an emotional experience that requires skilled medical teams and support from loved ones. As we see from this collection of stories, transplant is never-ending—it is a journey that continues. It is multifaceted, with many chapters, up and downs, hardships, and joys. Transplant changes people and relationships and provokes many emotions—guilt, fear, gratitude, worry, and responsibility. Despite all this, organ transplant is a gift—the gift of life—donors, either living or deceased, are heroes who selflessly give this gift to someone in need.

The first successful transplant took place in 1954 and was a kidney transplant, where a kidney from one identical twin was placed in another (Machado, 2005). Since then, transplant has become a common treatment for many illnesses, with over 126,000 organ transplants occurring worldwide in 2015 (World Health Organization & Global Observatory on Donation and Transplantation, 2017). A deceased organ donor has the ability to save up to eight lives as the liver, small bowel, kidneys, pancreas, heart, and lungs can be transplanted, resulting in the individual being given a second chance to live a long and fulfilling life (Ontario Health, Trillium Gift of Life Network, 2022). While many are familiar with the concept of organ donation from deceased donors (i.e., individuals who have died



and their family has donated their loved one's organs to someone in need), live organ donation is also an option for individuals in need of a liver or kidney transplant. Living donors can donate one of their kidneys or a portion of their liver to someone in need while they are still alive, resulting in the patient not having to wait until a deceased donor organ becomes available.

While transplant is proven to save lives, it comes with challenges. Patients who receive transplants are never "cured," as transplant is a treatment option and does not always rid a person of their illness. A host of new challenges may occur post-transplant such as having to take immunosuppressing medication to ensure the body does not reject the new organ. Often there are setbacks—bumps in the road—and sometimes the new organ fails, resulting in the need for a second transplant. In addition to these challenges, there are also ethical concerns such as risk versus benefit, the high demand for organs versus the supply of available organs, and the potential risks to live donors (Jonsen, 2012; Abouna, 2003).

I read these stories through many lenses, as my connection to transplant is wide-ranging. I have experience with a loved one who needed a transplant, am a donor family member, and spent years working in the field of organ donation and transplant. What struck me most when reading these stories was the resilience of the human spirit and the fight and will these authors had to stay alive. Many authors spoke about how transplant would not be possible without the support of family, caregivers, faith institutions, and other patients. Some of the stories detailed the importance of the medical team and stressed how a supportive (or unsupportive) team made all the difference. Many writers described transplant as a journey—a process that is ongoing. While the focus of transplant is mainly the physical act of moving an organ from one body to another, the writers of these stories spoke about the multitude of emotions felt throughout this experience: gratitude, guilt, and the responsibility felt for the gift given by those who provided the authors with a second chance at life.

## Support from Family, Friends and Others

In all of the stories, the writers described how the transplant journey was made possible by those who supported them along the way. These supporters and caregivers pushed the recipients when needed, gave love and support, were advocates and mentors, and provided a voice when someone needed to speak on the recipient's behalf.

Both Slakter and Crais wrote about how they relied on family and friends to help find a living donor. Slakter talked about how his family and friends lead the search for a living donor. "[M]y family and friends reached out across their social media networks to search for potential donors." Crais shared that he relied on friends and colleagues to spread the message that he needed a living donor. "I did lean on my friends and colleagues to get the word out about my need," he states.

While those searching for living donors enlisted the help of family and friends to find an organ, other writers were touched by the amount of support they received while going through their illnesses and recovering from their transplants. "[F]amily and friends supported me with the words of encouragement and an outpouring of love," writes Frantzen.

Support comes in many forms, and while family and friends provide love and encouragement, Gould connected with other heart transplant patients with whom she became very close and who helped guide her along the way. "[H]e put me in touch with two women who had received new hearts a few years earlier [ . . . ] They soon became my invaluable mentors and cherished friends."

## Transplant Affected Family

While family and friends played a critical role in providing love and support, the writers were quick to note that their loved ones were also affected by the transplant journey. Keefer reports, "It's not just the recipient who is emotionally impacted. Transplant also affects the caregiver." Some of the writers described how the transplant changed

their relationships with family members and how the change in family dynamics impacted others in their lives. Colace highlighted how caring for her daughter, who needed a liver transplant, changed their bond. “Over time, I became my daughter’s personal nurse . . . almost at the expense of our mother-daughter relationship.” Frantzen noted that he had been given a second chance at life but is cognizant of the fact that transplant was not easy on him or his family. “The best is that I am alive to tell my story; the worst is the toll it has taken on my loved ones and myself.”

### Medical Teams

While loved ones played a huge role in supporting the writers of these stories, many felt a huge sense of gratitude towards the medical teams who cared for them and were by their sides throughout the whole experience. Medical teams are tasked with being experts in the illness; however, many health care providers go above and beyond. As Ragin described, the medical team provided support on many levels. “Both my PCP (Primary Care Provider) and nephrologist were very supportive mentally, physically, emotionally and even spiritually.” The writers felt these acts of kindness, compassion, and empathy and described how they led to deep admiration for the medical team. Moran says, “I cannot say enough good things about my transplant team . . . It is truly amazing how each person expresses so much care as they attend to their patients. I am in awe.”

While medical teams were viewed as supportive by most of the writers, there were incidences where the medical teams did not live up to the writer’s expectations. Crais and Senghor described how medical professionals failed to inform them of the seriousness of their condition, resulting in a lack of awareness. “. . . I was completely unaware of the critical situation . . . Older physicians sometimes used a ‘don’t tell until it’s necessary’ philosophy that shields the patient from bad news.” (Crais). Not being open and honest with the patient can result in the patient not knowing how to manage

their illness. Senghor describes his experience with his physician, who did not provide information on lifestyle changes he should make. “The doctor did not give me any information about what foods to avoid or how serious my illness was. Later he would justify his silence by telling me: ‘I didn’t want to scare you.’”

In an example described by Frantzen, the medical team did not inform him about a policy change that would have allowed him to relist to get a second kidney transplant after his first was unsuccessful. Frantzen, who must resume taxing dialysis treatments twice a week after the failed transplant, says, “We spoke to the kidney transplant team numerous times and were very disappointed with them as they never brought up this policy change.” These incidents left lasting impressions on the writers, causing them to feel disappointed and untrusting of their care providers.

### Transplant as a Journey

Almost all of the writers describe the transplant experience as a *journey*—even after an organ is transplanted, the transplant experience does not end. Transplant is often inaccurately believed to be a cure to a specific illness; however, as many of the writers attested, they were not magically cured by receiving a new organ. Post-transplant, the recipient must adjust to a new regimen of lifelong medications, continue to attend medical appointments, and may experience new and ongoing health issues. Ryan wrote that she faced challenges related to the side effects of her medications, while Moran at first questioned if transplant was the right option for him, given the continued health problems he experienced post-transplant.

“. . . [T]here were now new issues and problems with which to deal. Side effects of the anti-rejection drugs . . . [I]n addition, being profoundly immune-suppressed . . .” (Ryan).

“Unfortunately, I returned several times in the next three months with infections leading to sepsis and pneumonia. These months were very difficult, and I was questioning my decision.” (Moran).

Despite sometimes feeling that the hardships of a prolonged medical journey are never-ending, the transplant journey also had positive aspects. Many of the writers talked about how the experience of receiving a transplant changed them. “This moment would not have possessed such deep meaning if it wasn’t for the journey that came before it—the transformative journey of transplant,” Keefer notes.

Transplant inspired other writers to give back and help others experiencing similar health issues. After their transplants, several writers were inspired to start new careers in health-related fields. Senghor attributes his kidney transplant as the motivation for pursuing his career path. “Thanks to my kidney transplant, I obtained a master’s degree in public health, wrote a sociology doctoral thesis on my disease, and obtained post-doctoral fellowships that allow me to further my work on health issues.”

## Donor

One of the most interesting aspects of transplant is the connection between the recipient and the donor—a relationship that can be complex and full of emotions. We saw from Ryan and Crais, who both received kidneys from live donors, how they struggled with how to find a living donor.

“I knew this would be a problem for me because how do you ask people to consider being a donor?” (Ryan)

“How could I ask anyone to give up their kidney, undergo elective surgery, encounter risks, miss work, and convince loved ones it was a good thing to do?” (Crais)

Several writers who received organs from deceased donors state that they think about their donors constantly. Callaci, as well as others, reached out to their donor’s family by writing a letter as a means to thank them for their gift. “I have not stopped thinking of my donor and their family in the years since returning home . . . I have reached out to the family with written expressions of my enduring and unending gratitude over the years through the proper channels but have yet to hear back,” Callaci writes.

Thinking about the donor and their family weighed heavy on many recipients who struggled with the notion that someone had to die in order for them to live, such as Colace, who writes about waiting for a liver for her very young daughter. “The most dramatic thing to overcome and accept was hoping for someone’s death. For Elisa to live, someone else had to die.” (Colace).

The emotions associated with receiving an organ were plentiful and ranged from guilt to worthiness to feeling pressure and responsibility to protect the organ they received. Some writers also expressed the unusual feeling of having someone else’s organ inside them, which again is tied to some of the ethical questions involved with organ transplant.

“An original, ‘factory-issued’ vital organ was expertly removed, and another person’s heart stitched in, vessel by vessel.” (Gould).

“‘You must take care of this organ,’ they told me. ‘You must protect yourself, prevent infection, protect your gift.’” (Graham).

## Conclusion

These stories highlight what it is like to receive an organ from a living or deceased donor. The writers are courageous and show a will to live and fight to stay alive. They describe the ups and downs of transplant, including waiting for an organ to be found, the roller coaster of emotions that come with transplant, and demonstrate that the transplant journey is never-ending. The authors allude that it takes a team to make transplants happen. The team’s support is instrumental along the way and includes medical professionals, family, but most importantly the donor—without them, none of this would have been possible. The selfless donor and their families are the reason why these writers received a second chance at life and provided hope, a future, and a sense of gratitude that they will carry for the rest of their lives.

## References

- Aboutina, G., M. (2003). Ethical issues in organ transplantation. *Medical Principals and Practice*, 12 (1), 54–69. <https://doi.org/10.1159/000068158>

- Machado, C. (2005). The first organ transplant from a brain-dead donor. *Neurology*, 64 (11), 1938–1942. <https://doi.org/10.1212/01.WNL.0000163515.09793.CB>
- World Health Organization & Global Observatory on Donation and Transplantation. (September 2017). Organ donation and transplant activities: 2015 report. Retrieved from: <http://www.transplant-observatory.org/download/organ-donation-transplantation-activities-2015-report-2/>
- Jonsen, A. R. (2012). The ethics of organ transplantation: A brief history. *Virtual Mentor*, 14(3), 264–268. <https://doi.org/10.1001/virtualmentor.2012.14.3.mhst1-1203>
- Oxford English Dictionary. (2022). Transplant. In *Oxford English Dictionary*. Retrieved May 2022, from: <https://www.oed.com/>
- Ontario Health, Trillium Gift of Life Network (2022). *Organ and tissue donation saves lives*. Retrieved from: <https://www.giftoflife.on.ca/en/>





## Commentary

# The Agony and the Ecstasy: Stories from Organ Transplant Recipients

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**Abstract.** Transplantation affords recipients of a donated organ a second chance at life. However, the gift of life can incur impactful costs to the donor, the recipient, and their caregivers. In this collection of stories, thirteen authors explore their journey to transplantation and afterward—from physical pain and deconditioning; to navigating well-intentioned but rigid clinicians; to developing a greater appreciation of life, their community, and their abilities. We explore the recurring themes woven throughout the stories, including the solemn responsibility of accepting an organ, the challenges of living a new life with a body and mind changed by transplantation, the difficulty of preserving one's sense of self when one's clinicians are dominantly focused on the organ, and the spectrum of gifts that organ donation and transplantation provide.

**Keywords.** Ethics, Living donation, Organ donation, Organ transplantation, Quality of Life, Narratives

## Introduction

Receiving an organ transplant demands all-encompassing sacrifices at every step: to become eligible for transplantation, an

organ must fail; to donate an organ, in the majority of cases, a person must die; and to receive a transplant, a patient must undergo major surgery. If all goes well, the recipient of the donated organ is committed to a lifetime of blood draws, clinic visits,

and medications that increase the risk of infection, heart disease, and even cancer.

Despite this sobering picture, organ transplantation has improved significantly since its advent. Kidney transplantation has been possible since 1954, while liver transplantation lagged behind. Liver transplantation was first achieved in 1967 after a series of unsuccessful attempts that resulted rapidly in death (Barker & Markmann, 2013). Even after technical mastery of the surgery was established, up to 50% of grafts were lost within the first year due to rejection until the development of cyclosporine in the 1980s (Azzi et al., 2013). Thus, the first thirty years of organ transplantation were marked by great advances, devastating setbacks, and complex challenges that are unique to the field.

Over time, transplantation has become safer, with low intra-operative mortality and first-year graft survival for recipients of the most common allografts—kidney and liver—approaching 90% or greater (Colvin et al., 2022; Kwong et al., 2022; Lentine et al., 2022). Supportive care and bridge therapies for transplant candidates have also improved, with advances in dialysis technology and heart assist devices allowing survival and improved quality of life while patients await transplantation. But as these stories show, the process of awaiting, receiving, and maintaining a donated organ remains taxing, sometimes ravaging the recipient's body, mind, and relationships.

This collection of stories highlights thirteen organ recipients of diverse backgrounds with widely differing paths to transplantation: we hear from American heart recipients, a Senegalese kidney recipient, and the mother of an Italian liver recipient. The stories speak for those who knew from childhood that a transplant was in their future, as well as for those who after losing consciousness, woke up with a heart transplant they did not know they would receive. In this commentary, we explore the common threads woven throughout these narratives. The themes involve a sense of duty—and dread—in accepting the charge of an organ, the difficulty of living a “second life” within a body altered by weeks to months of post-transplant illness, dehumanization of one's care when reduced to the outcomes of a single organ, and appreciation

for community, compassion, and the simple fact of consciousness after so narrowly averting death.

## The Encumbrance of the Organ

Viable organs for transplant are a scarce resource, with demand outpacing supply so rapidly that seventeen people die daily waiting for a transplant (Health Resources & Services Administration, 2022; Lentine et al., 2022). When an organ becomes available, it is a product of great sacrifice, requiring a living donor to give up a part of their body or, as is the case with deceased donors, their life. After a deluge of pre-transplant education, transplant candidates find themselves keenly aware of these harsh facts. With their gratitude often comes an abundance of guilt.

A common theme of being undeserving arises within this collection. Repeatedly, recipients describe an unwillingness to approach potential living donors. Crais writes, “How could I ask anyone to give up their kidney, undergo elective surgery, encounter risks . . . ?” Ryan similarly describes the impression that she must “impress” her potential donor to seem deserving, and even expresses a flicker of mistrust, questioning why anyone would take such a risk. Moran refused entirely to accept living donation even when offered, electing to wait an additional four years for a deceased donor kidney rather than expose his son to the risks of donation.

Accepting a deceased donor organ may offer little solace for the recipient; the donation can feel taken, rather than given. Colace, the mother of a pediatric liver transplant recipient and therefore the de facto acceptor, feels the blood drain from her body when she receives the organ offer. She describes “a miracle and a tragedy” —the donation the miracle and death the tragedy. She explains, “guilt grew in my heart . . . we were thieves.” Other authors also see receiving an organ as theft, but rather than theft from a donor, they describe a similar feeling about taking from other potential recipients. Frantzen asks, “Do I want to receive a liver transplant and deprive someone younger?” and Crais writes of the guilt of having a living donor kidney available when others don't have the

resources and social support to obtain a transplant at all. Being the receipt of an organ, some recipients find, feels less like a gift than appropriation.

After transplant, these feelings can intensify. “The morning after the transplant,” Crais notes, “I woke up with a feeling of huge responsibility.” Ryan expressed similar thoughts, saying, “[The kidney] had given me my life, and I was responsible for it.” While grateful, transplant recipients find themselves constrained by the organ: in all the stories, the care of the organ and the focus on maintaining function assumes paramount importance, reshaping the recipients’ lives to surround the care of the gift. Some patients find shame in imperfect outcomes. When considering writing to their donor’s family, Ryan finds that many of her fellow recipients had been reluctant to write, feeling that they were not “fixed enough” because they had ongoing medical issues and would therefore disappoint the family. To the recipient, the eventual loss of function of the organ stings of failure. Even after fifteen years with her living donor kidney, Crais describes her worry that her donor would be disappointed in her: “The call I feared most,” she said, “was to Linda.”

The feelings of unworthiness, guilt, and outsized responsibility can crystallize and turn a needed gift into an encumbrance. Graham rebels against the single-minded focus on the organ, the “unparalleled responsibility,” writing: “You must take care of this organ, they told me, you must . . . protect your gift. But who was protecting me?”

### **The Burden of Living**

The supreme responsibility of the care of the gift falls on recipients who, following complicated hospital courses, find themselves with bodies and minds not yet ready to care for themselves. The experiences the recipients describe mirror the early course of the development of transplantation: high highs and lower lows. Several recipients reflect on the waxing and waning of their emotional and physical strength in the post-transplant course. “It was the best of times, it was the worst of times,” Frantzen tells; “the best is [that] I am alive to tell my story; the worst is the toll it has taken on my loved ones and myself.” Callaci, describing his

first excruciating attempts at walking in the ICU following his heart transplant, found that “the most positive and painful moments . . . could sometimes be [the same.]” Keefer, who received a kidney transplant from a living donor as a teenager and a liver transplant from a deceased donor in adulthood, compares the “peaks and triumphs” to the “valleys. . . and trauma” of transplantation. The process of transplantation for even the most grateful recipient is, at best, a necessary evil.

Before and after transplant, recipients endure myriad hardships, both expected and unforeseen. Frantzen, during evaluation for liver transplantation, undergoes a pancreas biopsy that leaves him an insulin-dependent diabetic, a significant “collateral damage” from the process of transplantation. Following transplant, the recipients describe medical experiences ranging from modest to more complex readmissions for infection, rejection, and other complications. In the worst cases, these recipients find themselves in a body that has betrayed them, forcing them to relearn how to move, eat, and live. Graham describes her hair falling out in clumps, her skin developing abrasions at the slightest touch, her “explosive and terrifying” mood swings, her inability to recognize her face in the mirror leaving her “caged and alone in my own body . . . angry, hurting, and scared.” Frantzen echoes this—his life forever changed: “I live in a constant state of pain . . . sleep is a word foreign to me.” Transplantation, while rebuilding the body in a new form, can inadvertently destroy the old form.

Cognitive function and emotional wellness are frequently touched in the process of transplantation: up to 46% of transplant recipients report post-traumatic stress disorder (PTSD) symptoms (Davydow et al., 2015). Graham speaks about the trauma of her extended recovery course, comparing her chest tube stigmata to “bullet holes” and the IV site bruises that dotted her arms to marks from an abduction; however, she notes, “It wasn’t the physical trauma . . . it was that no one was surprised.” She was left underprepared for the months of recovery, the miles of walking to regain her function, and most of all, for the mundane way in which her clinicians viewed these trials. The lack of empathy that she experienced from some

clinicians in her story is the true violation. Colace, who relates a wonderful experience with caring and empathetic physicians, nevertheless finds herself recalling nights in the intensive care unit at every turn—the color yellow, reminding her of the ICU walls; the smell of disinfectant, of the hallways; the beeping of her car, reminiscent of the ICU monitors. After being gifted eleven years of her daughter's second life, her daughter is no longer with her, but the PTSD remains.

The gift of life here turns into the burden of living with an altered body and mind, often without the recourse of open discussion: "Recipients can feel guilty talking about anything but gratitude because they know they were lucky to receive a second chance at life," explains Keefer. Bound by guilt and unwilling to be ungrateful, transplant recipients sometimes find themselves unable to express themselves to gain support. For those who do, their journey is still unfathomable to most. Frantzen finds his friends and family "moving on," unable to understand his physical limitations months after receiving a transplant. Keefer notes the same, reporting that after learning about her earlier kidney transplant or checking in after her more recent liver transplant, friends frequently ask, "So you're good now?"—words that betray the support group's inability to understand the diverse "transformative changes" of transplantation.

Transplantation takes its toll not only on the patient, but also on their caregivers. Those closely involved in the process obtain a greater understanding of the journey, but also experience more significant reflected trauma. Transplantation compromises the maternal instinct in Colace in the attempt to best become her daughter's nurse; "I just missed being her mom," she writes, finding her relationship with her daughter stolen by the journey. As her daughter's primary caregiver, she finds herself a "shadow patient," affected by transplantation as much as her daughter. During the transplantation process, Crais found the same and notes that "One of the things I failed to do was focus on my family and their needs." She goes on to advise physicians to, "[M]ention to donors and recipients that they think about keeping their family's needs in mind front and center."

## The Loss of the Self

"Immediately after transplant," remarks Graham, "the team's focus is on survival. Survive the 30 days post-transplant. Survive the year." To her, this is a narrow-minded view: why would she want only a year? Why are the physicians not speaking of years, and decades? She comes to realize that the focus after transplant lies heavily on the needs of the organ, not the needs of the patient.

This finding is a shockingly common theme throughout the stories, present in almost all. Transplant recipients describe a range of attitudes in physicians and surgeons, but almost all find a strong and sometimes dehumanizing focus on the right thing for the organ above the concerns of the patient. Graham writes further, "What constitutes a major event for a clinician may not be of the same emotional value to the patient." Although her physicians rejoiced at the high-dose steroids keeping rejection at bay, she despaired at her thinning hair, her mood swings, and her insatiable hunger. Graham isn't alone in her concerns regarding the discrepancy between the primary goals of some transplant physicians and that of patients: ten of 13 authors discuss the importance of finding the right transplant physician, one who will address the concerns of the recipient rather than solely focusing on the allograft. "Cutting and inserting objects into human bodies is a normal practice for those working in transplant. . . . [it] is not normal for patients," writes Slakter, describing a time in which his reluctance to undergo a kidney biopsy resulted in his transplant physician terminating the treatment relationship. In this case, he did not wish to avoid the biopsy; he wanted his concerns regarding the potential complications allayed with a full discussion of risks and benefits. Regardless, he found himself with a new provider. Attempting to discuss her medication side effects and the trauma of her transplant course left Graham in similar straits, with a clinician commenting, "Well, at least they kept you alive."

The challenge of priority—should we attend most to the closely watched organ, or to the patient?—is not an easy one to remedy. While patient needs should be paramount, they are sometimes at odds, as seen here, with the needs of the

allograft. Furthermore, poor allograft outcomes compromise not just the donated organ and the individual patient; in the heavily regulated industry of transplantation, poor outcomes can cause the transplant program to face regulatory sanctions, which in turn may restrict transplant access for a wide swathe of patients served at the center. However, the patients who tell their stories here ask not for off-protocol treatment, but for understanding. Senghor writes of his difficulty in complying with medication administration times after his kidney transplant, largely due to his newfound post-transplant freedom to socialize. He wants to take his medicine and preserve his kidney, but he desires provider help in organizing the times to one that works both for the allograft and for him. “Transplantation allows patients to integrate into society,” he notes. After a long period of being absent due to the rigors of dialysis and kidney disease, Senghor wants to be seen as a person with a transplanted kidney, not as a kidney alone. Similarly, Graham describes a brief moment in which a physician turns to her and acknowledges the difficulty of her steroid-associated hair loss: “[F]or the first time I felt seen as myself again, for who I was.”

### The Gift of Life

Despite the ravages of the body and the trials of the mind, transplantation affords many a return to life. The authors find that sometimes the life they re-explore surpasses the one they left behind in organ failure. Slakter bicycles around New York with vigor he hasn’t felt since being a child; Lewis finds a career as a nurse and later a nurse anesthetist, a path he only dared take due to transplantation; Keefer gains love and the confidence to explore new places alone, without her safety net. “I dare to have a purpose in life,” says Senghor, sick from his teenage years; “transplantation allows [patients] to flourish as human beings.”

But even for those left with bodies that will never recoup the losses from organ failure, transplant surgery, and the months of subsequent recovery, transplantation affords appreciation of the life left to live. “Without the pain [of post-transplant

recovery],” Frantzen tells us, “I never fully knew the gift of life. [My transplant] taught me the meaning of love and sacrifice . . . receiving the gift of life is something I treasure every day.” Although his illness has taken away his ability to walk normally, eat normally, even relate normally to his friends and family, it has deepened his connection to his wife and his commitment to his life. Keefer, having seen two transplants, commits herself to advocacy and to exploring the life she has left; “the *quality* of life outweighs the *quantity* of it,” she writes, standing on top of a bench in the middle of a rainbow.

### Epilogue of Transplantation

All of these authors have found a purpose in the community. Powerful people, with or without transplantation, the authors have turned their futures toward helping others in their situation and to the field as a whole. Graham is a public speaker and patient advocate. Crais authored a patient’s guide to living kidney donation and transplantation. Senghor obtained a master’s degree in public health and studies the sociology of kidney disease. Moran takes advantage of his platform in his story to encourage donation. Gould builds her support group and finds “an abiding sense of community.” Lewis cares for organ donors and their families in the neurology intensive care unit (ICU). Keefer volunteers for a COVID-19 antibody trial to lend her gift to science, and Ragin has provided service in over seven transplant organizations and committees.

Through these authors, the gift of life has been received and compounded many times over to create a legacy that belongs both to the transplant recipients and to the donors who allowed them to live.

### Conclusion

At the heart of the journey of every author in this series is a yearning for compassion—compassion from the donor, in giving the gift; from their families, in accepting and supporting the patient during their transplant journey; and from their clinicians in incorporating the organ in the care of the self. Lying



in the ICU, Gould writes, “The needle pricks less when the phlebotomist calls you baby . . . nourishment comes in many forms.”

Transplant remains, to modern medicine, the greatest offering; the ultimate sacrifice from a donor, leading to the only chance at a second life for the recipient. In the words of these recipients, we see that the donation can be many things: an encumbrance, a burden, and sometimes even a form of loss. But to every patient, transplant remains a gift of life that leads them to become more than the sum of their—and the donor’s—parts. As Callaci announces, “Yesterday we walked; today, we dance.”

## References

- Azzi, J. R., Sayegh, M. H., & Mallat, S. G. (2013). Calcineurin inhibitors: 40 years later, can’t live without. *The Journal of Immunology*, *191*(12), 5785-5791. <https://doi.org/https://doi.org/10.4049/jimmunol.1390055>
- Barker, C. F., & Markmann, J. F. (2013). Historical overview of transplantation. *Cold Spring Harbor Perspectives in Medicine*, *3*(4), a014977. <https://doi.org/10.1101/cshperspect.a014977>
- Colvin, M., Smith, J. M., Ahn, Y., Skeans, M. A., Messick, E., Bradbrook, K., Gauntt, K., Israni, A. K., Snyder, J. J., & Kasiske, B. L. (2022). OPTN/SRTR 2020 Annual data report: Heart. *American Journal of Transplantation*, *22 Suppl 2*, 350-437. <https://doi.org/https://doi.org/10.1111/ajt.16977>
- Davydow, D. S., Lease, E. D., & Reyes, J. D. (2015). Posttraumatic stress disorder in organ transplant recipients: a systematic review. *General Hospital Psychiatry*, *37*(5), 387-398. <https://doi.org/10.1016/j.genhosppsych.2015.05.005>
- Health Resources & Services Administration. (March 2022). *Organ donation statistics*. <https://www.organ-donor.gov/learn/organ-donation-statistics>
- Kwong, A. J., Ebel, N. H., Kim, W. R., Lake, J. R., Smith, J. M., Schladt, D. P., Skeans, M. A., Foutz, J., Gauntt, K., Cafarella, M., Snyder, J. J., Israni, A. K., & Kasiske, B. L. (2022). OPTN/SRTR 2020 Annual data report: Liver. *American Journal of Transplantation*, *22 Suppl 2*, 204-309. <https://doi.org/https://doi.org/10.1111/ajt.16978>
- Lentine, K. L., Smith, J. M., Hart, A., Miller, J., Skeans, M. A., Larkin, L., Robinson, A., Gauntt, K., Israni, A. K., Hirose, R., & Snyder, J. J. (2022). OPTN/SRTR 2020 annual data report: Kidney. *American Journal of Transplantation*, *22 Suppl 2*, 21-136. <https://doi.org/https://doi.org/10.1111/ajt.16982>

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