Fall 12-15-2017

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The Gift that Keeps One Living

By Scott R. Axelrod

4100 Words

David Serur, The Rogosin Institute's Medical Director of Kidney and Pancreas Transplantation, sits waiting in his office. His window looks out onto Manhattan's busy Upper East Side. Car horns harmonize with ambulance sirens, as Starbucks cup-clutching people dressed business casual carry on loud conversations on their smart phones. Construction workers shout and wave to each other from atop scaffolding on competing worksites. Rogosin's waiting room is quiet except for a receptionist giving directions over the phone and an older lady loudly listing her medications to her husband who's more focused on reading how the Yankees did last night. Steps from Dr. Serur's door, individuals, couples, and whole families make their way into Rogosin's modest suite of offices and exam rooms tucked away on the second floor of an outdated-looking building on the New York Presbyterian Hospital/Weill Cornell campus. Pulling on a fresh lab coat and tightening his tie, Dr. Serur steps out to meet with potential kidney donors, potential kidney recipients, pre, and post-transplant patients. As he plucks the first appointment from the standing-room-only crowd who fill the small space, a few groans, some anxious sighs, and a couple of looks of frustration follow, as mostly everyone in attendance is already tired of waiting. Some might consider the impatience rude, but for patients in desperate need of new kidneys, having to wait any longer could kill them.

According to the National Kidney Foundation, 660,000 Americans are currently being treated for kidney failure—or, end stage renal disease (ESRD). And with only 30,000
kidney transplants having taken place throughout the country within the last year, only 6,000 of those came from living donors. Cadaveric organs, or those harvested and donated from the deceased, are not enough to cover the demand. We've reached the point of a living kidney donor shortage, as not enough people are volunteering to donate—not enough of the living are helping to save lives.

"Much of the shortage of living donors we're dealing with is based on people being scared of surgery and having a mistrust of the medical community," Dr. Serur said. "There needs to be more education about donation. We make sure that living donors are treated like VIPs. They dictate the pace of the process, and whether they ultimately decide to go through with the procedure is entirely up to them."

Living organ donors are the only surgical patients who derive no medical benefit from their procedure and hospitalization. The kidney is also the only major organ that can be donated in whole by a living donor, whereas both the liver and lungs could be donated in segments that eventually regenerate when grafted to the malfunctioning recipient organ. Liver and lung transplants are also considered more complex and difficult procedures that carry a significantly higher risk for both donor and recipient. A living donor kidney transplant procedure is not without risk, but donors are typically left with no long-term medical issues.

Marian Charlton, Rogosin's Chief Transplant Coordinator sits next to a neatly organized desk. Her Irish accent is soothing, but she's doing a lot more listening than talking as she interviews a potential donor who's chosen to donate altruistically—individuals willing to give an organ to a stranger, and to whom Marian refers to as "Donor Champions."
Marian functions as a donor advocate (the recipient has their own advocate) and details the full extent of the process, from all the tests, to all the appointments, to all the way through to what one could ultimately expect life to be like with one less kidney than they came into the hospital with. The potential donor laughs nervously and admits to being overwhelmed, but agrees that they want to at least find out if they're a match. Marian walks with the potential donor to Rogosin's phlebotomy lab where at least half-a-dozen vials are drawn for blood-typing, tissue-typing, cross-matching, and serology analysis. Test results take time, and more waiting ensues.

Potential donors are asked throughout the entirety of the process as to their motives for wanting to donate and whether they've been coerced or forced into giving up an organ. A psychiatric evaluation is also administered to ensure that any donors-to-be are mentally competent and understand what they're signing up for. The recipient's insurance company typically covers all medical costs of the donor. The kidney procurement procedure is still considered surgery and donors have to be aware that they now have one kidney doing the work of two, with no spare. One upside for the donor however, is that if they ever need a transplant themselves, they go right to the top of the list. But, any dreams of a football or boxing career are going need to be replaced with something less dangerous, like full-time journalism school.

Those able to get this far are reviewed by the entire transplant team who vote on whether the candidate meets the qualifications for transplant surgery in accordance with the clinical practice guidelines established by the American Society for Transplantation and the Consensus Statement on the Live Organ Donor. Not everyone passes, though,
and hopeful recipients are left waiting longer. The longer an ESRD patient has to wait for a new kidney, the chance of them not living long enough to receive one increases.

My dad, Alan didn't have to wait long. When he was told he needed a new kidney in 2007, I offered him one of mine. I met with Dr. Serur. I met with Marian Charlton. I met with a psychiatrist. I met with a social worker. I met with pretty much everyone at the Rogosin Institute. Then a few months later, I was able to refer to myself as a living kidney donor. I was obviously unconscious when I had my left kidney removed, but I've pieced together the procedure.

*Your surgeon signs their name to the side of your body that's about to be operated on to ensure that nobody on the surgical team makes a malpractice-worthy mistake. You kiss your tearful family and friends goodbye as you're whisked off to the operating room. Once inside, you climb aboard the cold, stainless steel table before being tucked in under a heavy warming blanket. Within a few minutes, your anesthesiologist has you count down from ten, even though you won't get past seven. That's the last thing you ever remember about your minimally invasive "keyhole" nephrectomy procedure. That's the last thing you ever remember about that time you entered a room with two kidneys, and were wheeled out with one.*

*The Donor and recipient are worked on simultaneously in separate operating rooms, with the donor organ harvested first. In most cases you're turned onto your right side—also known as a modified flank position—while propped up with pillows and strapped to the table to allow access to the left kidney. You've been catheterized so that you don't urinate on yourself and/or the surgical team. Your legs have been wrapped in*
intermittent pneumatic compression devices which are like large blood pressure cuffs used to prevent blood clots from forming while you're immobilized. You've already undergone a spiral computer tomography (CT) scan with intravenous contrast administration and vascular reconstructions to properly assess the renal hilum prior to surgery. This is the "map" your surgeon uses to study the anatomy of your kidney to ensure it looks healthy to sew into another person. The left kidney is more commonly used for transplants due to it having a longer renal vein—the vein that carries blood filtered by the kidneys back to the heart.

Wielding a #10 scalpel, three to four half-inch incisions are sliced into different areas of the abdominal wall. With a blade that thin, bleeding is minimal to non-existent, and a cautery device is used to sizzle away the now ruptured blood vessels before they have a chance to bleed. With the abdominal muscles moved aside with retractors, carbon dioxide is pumped in to insufflate, or distend the abdomen to give the surgical team enough room to access your kidney, and to avoid nicking any of the network of veins, arteries, and your other organs—there's a lot less room inside of the abdomen than one would think, as many anatomical illustrations are misleading. A silicone-like sleeve known as a GelPoint device is placed over one of the incisions, as rods called trocars are slipped into what are now essentially puncture wounds. One trocar is a camera that broadcasts a live view of your insides onto a screen, as the rest feature instruments and tools which are used to delicately dissect and separate your kidney from its soon-to-be former home. Your liver, pancreas, and spleen are all moved out of the way in order to reach your kidney. With the renal artery and vein dissected, the kidney is detached. Through a series of delicate procedures similar to operating an arcade claw machine,
the kidney is gently placed into an Endocatch bag and removed through a roughly three-inch-long horizontal incision just below your belly. As the trocars are removed all of your incisions are sutured with dissolving internal stitches. Your now former kidney is carefully transported and handed off to the transplant team next door.

Meanwhile, Dr. Barry Smith, President and CEO of The Rogosin Institute is concerned.

"Living donor transplants have slowed down significantly," Dr. Smith said. "Within the last year, most of our transplants involved kidneys harvested from deceased donors."

With the population ages, more cases of chronic, acute illness such as diabetes and high blood pressure are leading to more cases of kidney disease, and there aren't enough living donor organs to meet the needs of The United Network for Organ Sharing (UNOS) which includes over 122,000 Americans currently waiting for a kidney.

However, within the last year there's been a small, but noticeable increase in organs harvested from deceased donors, due to the uptick in opioid-related deaths. Transplant coordinators are also considering accepting organs from patients whose medical criteria previously disqualified them from being considered for transplants. As was the case in 2016, when researchers conducted the first HIV-positive to HIV-positive liver and kidney transplants. Devices designed to keep organs alive outside of the human body for longer than your typical cooler filled with ice, are seeing advancements in technology. But still, what's the point in having a technologically-enhanced kidney cooler, if there aren't enough donor kidneys available to be transported in it?
Dr. Smith believes that the middle portion of the country—in contrast to the Northeast region—is comprised of smaller, closer-knit communities with a significantly larger percentage of living donors. A kidney from a living donor has a greater chance of not being rejected and lasting longer than one harvested from a recently deceased or cadaver donor. Transplants are also more successful in recipients who’ve not undergone dialysis treatment. The longer a patient waits on dialysis for a transplant, the longer they’re potentially exposed the effects of kidney failure and dialysis, which include heart problems and infections. Side effects associated with dialysis include chronic inflammatory issues which could lead to patients having worse outcomes after transplants, including the potential for organ rejection. Preemptive transplants constitute a small portion of the total transplants in the country due to the simple fact that there aren’t many ESRD patients with the luxury of having a living donor on standby—like my dad did.

The shortage of living donor kidneys could potentially be eased by offering cash incentives, but the National Organ Transplant Act of 1984 made the practice of buying or selling human organs illegal. The language of the law explicitly applies to those who "knowingly acquire, receive, or otherwise transfer" a human organ, but doesn’t set out to punish anyone who unknowingly receives an illegally procured organ. So, while one won’t necessarily be profiting from selling off an organ, certain expenses related to the donation process can be reimbursed. This varies on a state-by-state basis as to how such payments are allocated, with most covering travel and housing expenses, and lost wages.
Dr. Smith also believes that stories about the rare instances of living donor transplant complications are another reason that people are scared when it comes to considering donation. In 2015, The University of California San Francisco Medical Center, was forced to temporarily suspended its living donor transplant program after a 28-year-old man died shortly after the surgery to remove a kidney to donate to his sister. Lapsing into a coma just over a week after the procedure, an autopsy later determined that the patient died from “lethal cardiac arrhythmia,” which is rare, but not a medical issue that would have been caused by the transplant team. The recipient went on to live with no complications and remains healthy with her brother's kidney.

"These stories get out and have a negative effect on living donor programs," Dr. Smith said.

Marilyn Davis adjusts the thin blue fleece blanket covering her legs as she sits back in her chair. Placing her crossword puzzle on the table beside her and next to a pair of paperback novels and a smartphone, she can reach out only so far. Tubes connected to a catheter in her arm keep her tethered to a dialysis machine, or a hemodialyzer—which acts as an artificial kidney to remove waste, chemicals and fluid from the 1.2 to 1.5 gallons of blood coursing through the human body. Out through an artery and back in through a vein, the machine whirrs and beeps as Marilyn has been in the dialysis unit for just over an hour, with two more to go. Marilyn plays out the scenario again two days later to finish out the third day of her three-day-a-week ritual. Marilyn is just one of roughly 470,000 dialysis patients in the country.
"I've been coming here for a few months already," Marilyn said. "It's just something I have to do, like going to work. They don't have to find me a perfect kidney. I'm 71—I'll take what I can get," she added, before turning back to channel-surfing daytime TV.

The Rogosin Institute was established in 1955 and named in honor of Israel Rogosin (1886-1971), an American textile industrialist and philanthropist. The Rogosin team coordinated the first hemodialysis unit in the metropolitan area as a treatment for kidney failure. In 1962, the unit moved to New York Presbyterian Hospital/Weill Cornell Medical Center on Manhattan's Upper East Side, where in 1963, they performed the first successful kidney transplant in New York City. Independently operated, Rogosin provides inpatient and outpatient services for those living with kidney disease, diabetes, lipid and cardiovascular disorders, and cancer.

Dr. Sandip Kapur is Chief of Transplant Surgery and Director of the Kidney and Pancreas Transplant Program at New York/Presbyterian/Weill Cornell Medical Center. An internationally recognized expert in pioneering transplant techniques, Dr. Kapur specializes in adult and pediatric kidney transplantation and whole organ pancreas transplantation—and that's just going by what it says in his bio. Dr. Kapur reiterated Dr. Serur's belief that the only way to keep living donor programs afloat is by continued advocacy and education. He also emphasized that while living donor transplants have relatively low risk for donors, the procedure itself is technically not easy to perform. Laparoscopic surgery only allows for small movements within the confines of a small, enclosed space.
"I've been performing transplant procedures for over 25 years," he said. "I'm able to see the operation in my mind, but don't know what I'm going to encounter until I'm in there. Operations that I thought would be routine, have turned out complicated. While operations that I anticipated would be difficult, ended up running smoothly."

You've already counted down from ten, getting no further than seven by the time the donor kidney has been harvested and handed off to your surgical team. You've been painted with a generous coat of antiseptic Betadine that will leave you stained orange for the foreseeable future. The human kidney itself is bean-shaped and the coincidental reddish-brown color of a kidney bean. Weighing in at just under half-a-pound and about the size of a large fist, the organ comes complete with a renal artery, renal vein, and ureter. Wielding a #10 scalpel, your surgeon makes a long incision into the lower part of your anterior abdomen. This wound will eventually heal into a scar that could confused for a C-section or a failed attempt at seppuku, depending on your size. If this is a living donor-type situation, the family member, friend, or altruistic stranger in the adjoining operating room is already on their way to recovery after the relative luxury of "minimally invasive" surgery.

The actual transplanting part of your transplant is considered an "open" procedure. The layers of skin, fat and muscle have been cooked through with the cautery so that the blood vessels don't have a chance to bleed. The work space is held open with retractors as a surgical nurse assists to both suction and blot away the blood that’s bubbling up into your abdominal cavity. Your procedure is referred to in textbooks as heterotopic, meaning that your surgeon is currently fashioning a pocket, or making room in your
pelvic region as your existing kidneys are being left where they lay. Heart and liver transplants are orthotropic procedures where the new organ is installed in the same place as the original organ. The original kidneys are not usually removed unless they’re causing severe problems such as uncontrollable high blood pressure, frequent infections, or are greatly enlarged. After your new kidney has been placed, the renal artery and vein of the donor kidney is sewn by hand to your external iliac artery and vein. Your new kidney should "pink up" at this point with its fresh blood supply. The ureter is sutured to your bladder. A check to make sure urine is being produced is made. Satisfied, the team goes through the process of closing you up with a combination of internal and external sutures.

Rabbi Josh Sturm spends his days playing matchmaker. But as the outreach director of Renewal, a Brooklyn-based non-profit that works to save lives through kidney donations, he couples up recipients with donors, rather than couples looking to get married. Renewal, which has been operating for just about eleven years, has helped facilitate several hundred transplants. And while the organization never turns anyone away, its waiting list is 95-percent Jewish. ESRD patients coming to see Rabbi Sturm at Renewal are taught how to sell themselves to save themselves—a tagline the rabbi admittedly wished he’d coined himself. With the help of a graphic designer, clients are taught how to market themselves much like they would in creating a social media account or a dating profile.
"We don't have a line of donors waiting outside the door," Rabbi Sturm said. "What we do is make sure we're marketing a healthy-looking individual. Anyone considering donating a kidney is going to ask themselves if they're making a good investment."

Armed with both digital and printed fliers, it's left up to the client to spread word of their plight. From posting on Facebook and Twitter, to putting up pages in supermarkets, synagogues, and bingo parlors, anything the client can do to let people know that they need a kidney is recommended. What makes Renewal unique is that once a donor is found, the organization takes over.

"It's about getting that donor through the finish line," Sturm said. "The donor is a hero and needs to be treated like one."

From arranging all medical appointments, to providing travel, housing, and meals, a donor's hand is literally held all the way up to the day of the surgery and through the entire recovery process. Sturm himself has spent countless hours with family members in waiting rooms. He's also always bedside, offering prayers and comfort to donors and recipients just before they're wheeled into the operating room.

"You get desensitized to it after a while, Sturm said. "But it's impossible not to get emotional when you see people go from being so sick, to having a little part in making sure they get well and stay well."

Sturm claims that 15-percent of all altruistic kidney donations in the US come from Jewish communities. The rabbi often meets with other community and religious leaders in the hopes of helping them organize similar programs.
"We're a community-based model," Sturm said. "We don't have a secret recipe. We want you to steal what we've been lucky enough to be able to do."

After breaking his ankle and moping around the family room for a few weeks, my dad was hospitalized with pneumonia. A house nephrologist at Staten Island University Hospital told him that the type 2 diabetes he'd been diagnosed with a few years earlier had already caused damage to kidneys and that undergoing a preemptive kidney transplant before he'd ever have to spend time hanging out with a dialysis machine was something he should seriously consider. My dad's wiseass response was:

"No problem, I'm sure my son will give me one of his."

I made that up, I wasn't actually there and can only presume the conversation went like that—my dad was a funny guy.

In 2007, my mom, my sister, and I found ourselves at the Rogosin Institute a few weeks after hearing the word "transplant." All three of us ended up being perfect matches for my dad, but I insisted that I didn't want either of them to have to go through what I knew was likely going to be scary and painful situation. If my dad needed a kidney, I wanted it to be mine. It was Dr. Serur himself who asked me why a healthy 27-year-old wanted to donate an organ to a 58-year-old man with a number of chronic illnesses. But it was my kidney, and my family wasn't asking for my dad to be put on the waiting list, given any special treatment, or for an altruistic donor to come flying in to save the day. This was also more than my just dad we were talking about here. This was my best friend and I wasn't going to let anything happen to him, let alone let anyone talk shit about him.
Everyone says that their dad is the best; mine was the best. This was the oldest guy at the Nine Inch Nails concert at Madison Square Garden in 1995. An unknown band called Marilyn Manson opened the show and my dad went out and tracked down their album the next day. For a guy who retired early due to a back injury, he'd come pick me from school every day playing new music that he'd just bought.

"You have to hear the new Radiohead." he said. "It's called OK Computer, and it's fucking awesome."

This was the guy who I wasn't ready to lose or see hooked up to a machine to have his blood cleaned.

This was a guy who'd spend a whole day playing Nirvana albums on repeat and cared about dozens of other things that most people in their 50s don't know about or have any interest in. This was the guy who went to see the film Fight Club in the theater with me, and then drove with me into Manhattan to meet my literary hero, Chuck Palahniuk—speaking for me when I turned fanboy and didn't know what to say. This was the guy who I wasn't ready to lose or see hooked up to a machine to have his blood cleaned.

Over the course of the next few weeks during that summer of 2007, I lived through a montage of all the testing required of a living donor, and then suddenly it was surgery day. After those aforementioned tearful kisses goodbye and my surgeon, Dr. Joseph Del Pizzo, signing my left side—I asked him to please make sure I wasn't getting breast implants—they took my left kidney, which answers the question of why I have a highly detailed black and grey kidney tattoo inked onto my left arm.
In 2010 my dad died from a non-kidney related illness. I watched as the light went out in his eyes and heard his death rattle. The scene plays on a loop in my head every day. Sometimes I make it play for reasons I can't even explain. I quoted Eminem lyrics in his eulogy. Hearing the news of his passing, an acquaintance barely offered her condolences before blurting out:

"So, does that mean you get your kidney back?"

I'd rather have my dad back. He can keep the kidney—it was a gift.