

*I haven't posted a blog on-line, but through my comments in a Facebook note and my comments in response to some discussions on the LDO forum (such a great resource!) I've ended up making a blog of sorts. So this is a long (9-page!) record of my journey through the kidney donation and first six months recovery. I'm "Sarah in Maine" on the LDO forum, and welcome any personal emails to discuss the decision to donate, the list exchange process, and recovery.*

I donated my kidney at the Lahey Clinic in Burlington, Massachusetts on October 27, 2008. The donation was 'non-directed' (meaning, I didn't know the recipient) as part of a list exchange, (meaning that my mother benefited by getting bumped to the top of the wait list for a deceased donor kidney), and she received her transplant on November 26, 2008.

#### **November 4, 2008. First Entry on Facebook Note re "The deal with Sarah & her mom & their kidneys"**

Okay, so this seems perhaps a useful tool for telling the story to the random assortment of Facebook friends who've found me but don't know what's really going on. About 7ish years ago, we discovered that my Mom's kidneys were failing due to a long term side effect of medication she'd been on her whole life. Neither my sister nor I were the right blood type, so a transplant from us was not an option. At that point, Mom made lots of changes to her diet and lifestyle and managed to slow the decline significantly. We all went into a stage of denial for 5 years or so. Then, as her kidney function began to approach the need for dialysis, her doctors gave the wake up call that now would be the best time for a transplant. Her one friend with the right blood type turned out not to be a good match.

Around this time, I heard of 'paired donation' where folks with willing but incompatible donors (that's one donor-recipient 'pair') get their data jammed into a computer program designed to find an equal but opposite 'pair'. However, Mom would have none of it - the martyr-mom position, as I call it. After about a year, though, dialysis loomed in the foreground and Mom's surgeon told her of a new technique whereby certain 'subtypes' of A blood (me) can donate to O blood recipients (Mom). She was willing to let me get the medical work up for that. Although I'm not the right 'subtype', I finally found the chink in her armor and got her to understand that I WANTED to donate a kidney for her, and that the paired exchange was even better as it allowed me to help not only her, but another recipient who needed a kidney (and, in fact, 2 others as they got a boost up the wait list). So during fall of 2007 I had nearly every test known to mankind and got cleared to donate a kidney. They only let the healthiest of folks donate.

So, from January 2008 my Mom & I were in the paired exchange database. Unfortunately, because O blood type is the 'universal donor' it is also the most selective recipient. That means that Mom can ONLY get a kidney from an O donor. It also means that most willing O donors are more likely to match their intended recipient and so there are very few of them in the paired databases. Bummer. So, we waited & waited. Mom went on dialysis in February 2008. She is one of the lucky ones that handles it very well and has so far been able to keep her full time job, going to dialysis 3 nights a week for 4 hours a pop.

Then we started to look at our next option. For a recipient with the right medical criteria and who has been on dialysis and in the paired exchange database for a certain amount of time, the New England region of organ allocation allows for "list exchange". This is where the willing but

incompatible donor (me) gives a living kidney to the most medically needy recipient at the top of the wait list for my blood type, one who doesn't have a willing donor of their own. As soon as that has been done, my Mom pops up to the tippity top (exclusive of pediatric patients) of the wait list for her blood type to receive a "deceased donor" kidney. This way, instead of the 5 year waiting time, her time waiting for the deceased donor kidney may be as short as days or weeks. I donated my kidney to an unknown recipient on October 27, and now we wait for the call for my Mom.

The gruesome and morally difficulty part of it is that it means we are now waiting for some family's tragedy to bring the miracle of life back to my Mom. That's something that you can't exactly wish to happen quickly, you know? And there is no guarantee of when the call will come in. However, we were originally set to do this back in June, but turns out there were others ahead of us in line (they only allow 2 of these list exchanges to be pending at any time, I'm told). Those folks received their deceased donor kidneys about six weeks following the living donation, and we hear that is a long-ish time. It could come in any day. The surgeons review the quality of the kidney to make sure that my Mom gets one that is the best possible for her, with least likelihood of rejection. So...now, we wait!

#### **November 29, 2008 Second Entry on Facebook Note.**

So, for a quick update. On November 26, my mother received her kidney. We are so grateful to the deceased donor and hope that the family of the donor finds some solace in the person's gift and ability to share life with others while giving up his/her own. It was a 3 hour operation for my Mom (compared to the 5 hours it took them to extract mine!) and today, 4 days later, she is back to eating real food & is walking around the hospital halls even faster than I am! She should be out of the hospital by Monday! Although she'll have much closer follow-up scrutiny as they perfect her cocktail of immunosuppressent drugs that allow her to live with a foreign organ inside her belly, her recovery is otherwise going to be less painful than mine, I'm told. Less overall cutting inside the torso. For those who are curious, they do not remove her 2 broken kidneys (with some diseases where the kidneys become enlarged or particularly deformed, they might do so, but my Mom didn't have that kind of kidney failure), so she's walking around with 3 kidneys in her body while I walk around with one!

#### **December 6, 2008 Remembering surgery**

Okay, so I'm 2 days shy of being 6 weeks from my voluntary nephrectomy (kidney donation) of October 27, 2008. I want to remember some of my surgery experience before I forget it.

I didn't have to do any bowel prep the day before, but had to have 24-hours of clear liquid-only diet (jello, broth, gingerale). Surprisingly, that wasn't as hard as I thought it would be. Sunday my husband and 7-year old daughter and I drove down to the hotel that was about a block from the hospital. My sister with her 2-year old twins and my mother (the ultimate recipient) came out so we could enjoy some pool time with the kids and have dinner together at the hotel restaurant (only liquids for me – mostly water, but I allowed myself one short whiskey toast, as it is a clear liquid!). That night I gave my Mom a kidney-bead necklace as a gift – yes, it got us both teary! And I had gotten 2 malachite kidney-shaped stones: one for my daughter and one for me to hold onto during the surgery. The beds were SOOOO comfortable, it was a nice treat that I'm glad we did. Next morning was early: awake at 5am to get to the hospital for 6am check-in

time. Hubby & daughter came with and my Mom met us there. After I had to change into robes I could only have one person with me, so my Mom was allowed to come into the surgery prep area while hubby & daughter went off to the pool and other entertaining things so that she wouldn't be too worried. I really wasn't nervous, just intrigued by the process. The only thing I was really nervous about was that I'd lose the malachite stone, but they allowed me to tape it into my hand! My Mom was there until I was put under, and actually I didn't realize when I was going under as they said they were giving me something to calm me (didn't call it anesthesia) and I was out like a light after that! Or at least, I don't remember anything from then on!

Woke up several hours later in the recovery room, with my Mom by my side. My surgery was about 5 hours long: a bit complicated because of my having a third vein that was attached kind of around behind where others normally are. But I was just thankful that they were able to do it laparoscopically and not need to make it open, as I'd been told there was a slightly increased chance of that. I wasn't nauseous, but had an oxygen mask on that kind of freaked me out when I woke up. I was on a morphine drip (not a self-controlled pump, the nurses administered it). I was quite a bit out of it, and clearly my body was hurting, but I didn't feel much sharp pain. The dry mouth drove me nuts, and I kept my Mom busy giving me ice and those spongy-water things.

I don't remember how long anything lasted, but they got me up to my own room eventually & I just slept an awful lot. I ended up being in the hospital for 5 days: not discharged until Friday 10/31. That was longer than I'd thought, but I was glad not to be rushed about. I was having a tougher time with the walking than I'd expected. And on day 3 they said that my creatinine level was still 1.6 and they wanted that to go down more. It must have by Friday, as I was discharged. At my one-month check up it was at 1.4, but I don't yet know how that compares to pre-surgery or my discharge level.

### **December 27, 2008 (Eight weeks post-op, responding to a LDO thread question about recovery during the first 6 weeks)**

Greetings, well, I'm officially 8 weeks post-op today, so I'll share a bit of my recovery. I was in hospital for 5 days, and ended up taking painkillers for a week and a half total (morphine drip first, then vicodin then oxycodone in hospital, then for some stupid reason they gave me vicodin at discharge but I didn't let them keep me on it, as it made me nauseous and so went back to the oxycodone). I wasn't particularly good about getting my walking in...certainly not like I thought I'd be, and I had a painful bowel issue as a result that thankfully resolved itself without returning to the hospital. I basically slept through the first 2 weeks! Attire was loose PJs or nightgowns ...being female the nightgowns are best for zero pressure on the incisions! I've got a 3 inch incision on my left, about even with my belly button, and 3 small lap incisions: one up from the big cut, one down from it, and one just in the top of my belly button.

I started driving again after 2 weeks & a couple of days, after my mother-in-law left and I needed to get my daughter to/from school. Only did the bare minimum needed at first. But it was nice to get out in public again and helped to start to shake the cobwebs from my brain. I did a LOT of hanging out on the couch and reading for fun and napping.

Towards the end of week 3, I was antsy to work...figured if I could spend so much time surfing the internet, I ought to be able to work some too. (I'm an attorney, so have the pleasure of telecommuting from home on occasion with lots of writing/analysis projects.) I did a *\*very\** little bit, which made me feel satisfied, but I'd have never attempted if I couldn't be in my PJs still and saunter back to the couch for a nap periodically.

During week 4 I pushed myself too hard. There were two different evening events (a dinner and a cocktail party) that were work related and I thought I could handle. I did manage to handle them, but it was surprising how tired even the smallest things still made me.

During week 5 (Thanksgiving week) I was preparing to travel to Mass to meet up with my sister for the holiday when we got the happy news that my Mom got her kidney. So we went down there (the holiday travel was planned with the slight anticipation that this could happen) and I was bopping between the hotel and the hospital and the house full of young kids. Again, not that I was actually DOING anything, but it was more tiring than I'd have expected. Of course, the adrenaline from the excitement of my Mom getting her kidney helped to keep my energy levels up.

I went back to work in the office the beginning of week 6. Brought a pillow with me to help make sitting more comfy, and left early most days that I could. In hindsight, I ought to have stayed home one more week. I found sitting with that 90 degree angle between lap & torso to be uncomfortable after a little while. Its getting better now. I only could fit into regular pants by week 7 (my work skirts sit low enough on my hips as to not be bothersome), but even now I can feel it -- not pain, per se, but sensitivity and discomfort. I'm still walking slowly and cautiously, but I'm leagues better than when I first got back to the office and was practically creeping around! I still get tired quickly, and am really best if I can get to bed by 10pm or earlier...those days I stupidly stay up later I am truly paying for it the next day. Keeping water in me is a huge deal too. And even now, if I seem to be feeling good & 'pushing it' one day, I'm bound to pay for it the next day and feel wiped all over again.

### **February 22, 2009 (approximately four months post-op)**

Well, its true what they say, I think. That it takes 6 weeks to get 80% better and 6 months to get back to 100%. For as much as anyone can tell, I'm 100% back to normal, but I know that I'm not *quite* there. I am way more conscious of my body around, inside & behind my scar than I think I ought to be. I can do just about everything I was doing post-op, but am still not quite up to sit-ups. I started a yoga class a couple of weeks ago and, while it is possible to do some of the sit-up type positions, it is very clear to me that I am not 100% in terms of ab strength! Now, if I was more regular in trying to work those muscles back into shape it might be a different story. But for my slow & random exercise pattern, I'm not quite there.

Still haven't heard from my direct recipient. That will always be a bit of a question in my mind, I think. Is he OK?

### **May 1, 2009 (in response to a question on the forum about how to tell your children)**

My daughter was 7 when I donated my kidney. I started my 'work up' in August '07, and got approved and put on the paired exchange database in January '08. In February '08 my mother

finally went on dialysis, so at that point we explained that Grandma was sick (I had to go down to help out during surgery to insert the catheter and help with her first few times of dialysis) and she knew that Grandma couldn't go swimming & couldn't get big tight hugs with her catheter. But I didn't mention to her that I was going to be donating my kidney or having surgery until much closer to the time it was actually going to be scheduled. For a while there, it looked like my turn would come up in June, so in early May I first mentioned to her that I would be able to help Grandma be healthy again (and be able to swim and get hugs) by having surgery to share my kidney. I thought I was giving her a couple of weeks to get used to the idea. Turns out I wasn't able to donate in June anyway, so she had longer, and I'm glad of that.

Over the summer, I'd periodically mention it and ask her if she had any questions. I explained to her that while I was in the hospital Daddy and her other Grandma would stay with her. I told her that I'd have a scar on my belly and would have to stay home for a while and would be tired and she might not be able to snuggle tight with me for a while. So I tried to give her some info on what to expect from a practical perspective: how it would affect HER life. Once we had a surgery date scheduled (about 4 weeks notice), I made a point of discussing it more. She really wasn't interested in the biology of the kidneys themselves, just more scared about being alone and without me during the hospital stay.

I also went on the kidneyjewelery dot com website (great spot!) and bought a couple of kidney-shaped malachite beads. My daughter likes collecting rocks, so the night before (we all stayed at a hotel together) I gave her one and told her I was keeping one with me (I got the nurse to tape it to my palm) and that she could hold hers and think positive thoughts about me while I was in the surgery if she was nervous or scared. She and my husband came to the hospital in the morning with me, but once I went in, my husband took her off to swim at the hotel pool and visit with friends so that she would be distracted (I had other family to hang around the hospital & make sure I was OK).

She came in to visit me on the day after my surgery, and was fine with it. She wasn't interested in seeing my scars right afterwards, but now (almost 6 months later) she likes checking them out.

Even though my daughter is 7, she usually crawls into bed with us by the early morning hours and she sleeps like a contortionist! So I know that I couldn't have her in bed and unknowingly kneeling me in the side all of the time after surgery. So I prepped her in advance that she wouldn't be able to snuggle tight for a little bit and would have to be extra careful about my left side. I also decided to sleep in the second twin bed in her bedroom. I figured that if I just told her not to come into our bed, she might forget and just return to her habits. Also, that would deprive her of a snuggle with her Dad. So by me being in the twin bed, it helped when putting her to sleep -- I could lay in there with her while we read -- and when she woke up in the middle of the night it was unusual enough to remind her that things were different so that she didn't automatically climb in next to me. She was either glad that I was in the room with her, or else would go in with her Dad.

I don't know about younger kids, but by age 7 she was certainly cognizant enough to understand about not climbing on me and getting hugs on my right side.

### **May 17, 2009, almost 6-month check up: thoughts on the “list exchange”**

So, today I have the joy of collecting my urine for 24-hours so that the creatinine data will be given to my doctor before next week's 6-month check up. Such a lovely process! But I thought I'd talk about the “list exchange” option.

A list exchange is a variation of a paired exchange: it allows an incompatible but willing donor to help their desired recipient get a kidney. But, unlike a paired exchange, the recipient does not get a *living donor* kidney, it instead gets a *deceased donor* kidney off the ‘wait list’, so the value of the ‘exchange’ is not quite equal. First: a word on language. Some folks refer to non-living donor kidneys as ‘cadaver kidneys,’ and, admittedly, it's a shorter way to say it than “deceased donor kidneys.” However I was very politely reminded on the LDO forum that the families of deceased donors can be offended by their loved on being referred to as merely a ‘cadaver.’ Very impersonal, and particularly difficult to take after the tragedy of losing the loved one. So the preferred terminology is deceased donor kidneys.

Back to the main topic at hand. I've been told that list exchange is not an available option in most of the UNOS regions; however it IS available in the New England region. Honestly, it poses a few more moral dilemmas than a regular paired exchange. The way that my mother benefits is because, instead of having to wait approximately 3-5 years on the ‘wait list’ for a deceased donor kidney, once I made my donation, she gets bumped to the tippity top of the wait list (exclusive of pediatric patients, who retain priority) and so receives her deceased donor kidney – and gets to end dialysis! – within a matter of weeks instead of years. There is some moral question about whether the exchange is equal: I give up a living kidney and she gets a deceased kidney – we all know that there has been data suggesting that recipients have better outcomes with a living kidney transplant. That moral issue was a pretty easy one for me to deal with, though: the way I looked at it, if I had been unwilling or medically unable to donate, the best my mother could have hoped for would be a deceased donor kidney anyway. So the benefit of time off dialysis and not having to have the surgery to create the fistula clearly outweighed the difference in quality of organ. [Of course, neither me nor my Mom had any major complications, so it remains easy to feel good about that decision!]

But the bigger moral question, I think, has to do with the rest of the folks on the wait list. I do not know how many individuals who lack willing donors my Mother “jumped” in line. I don't know their health circumstances, how long they've been waiting (though probably some have waited the 3-5 year average), or why they don't have any willing donors. I don't know if they are told that they get jumped in line (I assume not.) And often in literature encouraging living donation, you hear that people *die* while on the wait list for a kidney. I always cringe when I hear that, because I have no way of knowing if the particular timing of my donation and my Mother's transplant ultimately played a role in one of those deaths. That really bothers me. And this is not just hindsight. I had thought about this aspect of the list exchange well before we did it. But I'm not altruistic at all: I wanted my daughter to have more time with her grandmother healthy. I wanted to prevent my Mother from having another surgery to put in the fistula. I was quite willing to risk this harm to another in order to help my Mother get off dialysis and back to a more normal life quickly. I will always have to live with that knowledge.

Add to all of that the issue of O blood type. My Mother is type O: the universal donor. I believe that one of the reasons we couldn't find a living pair in the paired exchange is because most willing O donors are far more likely to be compatible with their intended recipient than other blood types. This means that the O blood types on the wait list get a particularly raw deal and are probably more likely than other blood types to be 'jumped' by the lucky recipient in a list exchange. I don't have any data on that, but it seems supported by common sense. (This leads to a general moral question about organ allocation from living and deceased donors who are blood type O, but that rant is for another day!)

Of course, one other way I resolve these moral dilemmas in my head is because I know that I donated my healthy living kidney to a recipient who did not have a willing donor. Although I'm told that he was at the 'top of the wait list' for my blood type, I don't know any other information about his health or history. For all I know, he may have been one of those soon to die on the waitlist had I not made my donation. I find some solace in that. And perhaps it is better that I don't get to meet him. If I were to find out that he was doing fine and could have chugged along on dialysis for 3 more years without major health risk, I might go back to wondering about those O recipients dying again.

I don't know about other centers, but my transplant center did not let me meet my recipient before the surgery or during my hospital stay. I gather that this may be similar to the variation in policies across transplant centers about non-directed living donors meeting their recipients. They did inform me that he accepted The-Kidney-Formerly-Known-As-Mine fine and was recovering well. Due to a paperwork mess up, I discovered his name a couple of weeks out. (Good thing I'm not a crazy-stalker though I did try, without success, to find out about him on Google!) And about one month after surgery my social worker offered to get us in contact if both of us were willing. I had made it quite clear before surgery & at the hospital that I was more than willing to meet, but I also didn't want to make him uncomfortable. As with any anonymous donation, I assume, it's a weird thing to be part of – and very weird to have donated without seeing, first hand, the positive impact on the recipient's health. I suggested that they give him my number and that way he could contact me if/when he wanted. When I went in for my 6 week check-up, my social worker said that he had called me, but didn't feel comfortable leaving a message on my answering machine. I haven't ever actually heard from him. The intensity of my curiosity to meet him has diminished over time (I felt much more closure after my Mother got her kidney and I could see her improving health), but I still do wonder about him.

Last thing to comment on for today is that doing the list exchange makes it very complicated to answer people's questions. I envy those who can just say: "I donated my kidney to my mother." Even the paired exchange program is getting more well-known now, so saying I was in a paired exchange seems relatively easy. I usually say that I donated my kidney on behalf of my mother, and God help the fool who actually asks me what I mean by that. Then I go into this whole long-winded explanation all over again!

#### **June 4, 2009 – Comments added to the thread about "Low GFR at 6-month follow up"**

Just as an update & to add data to our informal data collection group here, I had my own 6-month check up last month and, despite my interest and planning and making sure they gave me a 24-hour urine test instead of just a blood test, I *still* managed to forget to ask expressly about

GFR! (I can't help but wonder if, because my surgeon didn't mention GFR, it is because he thinks it is not a meaningful measure in living donors?)

But I did ask for my creatinine numbers, and have subsequently run them into the GFR calculator on NKF's website. Pre donation I was 1.1 = GFR of 59, day of surgery 1.7 = GFR of 36, 1.4 by hospital release = GFR of 45. Then he gave me two numbers for my 6-month check up: the 24-hour urine showed me at 1.3 (GFR = 49) and the blood work showed me at 1.5 (GFR = 41). He thought the increased blood work may have been dehydration related, and given that I had my blood drawn the Tuesday after Memorial Day weekend when I was out in the sun all day long and not drinking as much water as I usually do, that makes sense. But still the 1.3 / GFR 49 number is not particularly re-assuring. Good thing this whole thread has clarified the issue for me so that I'm not in panic mode, but it does speak to the problem of defining CKD in a meaningful way for 2-kidney as well as 1-kidney folks.

Clearly there is stuff I need to think about here, as GFR of 59 BEFORE donating certainly seems to be at that cut-off line. I know I am 100% healthy otherwise, but I don't recall anyone mentioning to me that I was right at the cut-off. I didn't ask for my numbers then, but took the transplant team at face value that I passed and was healthy enough to donate. Pros and cons of having a bright-line test, of course. But that does go to the 'informed consent' that is such an issue. (Knowing me, I would have donated anyway, but its problematic that I wasn't given the meaning behind that number.)

Well...I'm fresh from having run these numbers through the calculator, so want to give some thought to it. I think I'll be writing a letter to the center &/or surgeon to share my concerns.

#### **June 14, 2009 – Ruminations on My Six Month Check-up**

Well, I had my six month check up in the end of June. I asked for the 24-hour urine test, and also did a blood draw. I don't think they were going to do the urine test, but when I asked for it, they let me. Beyond that, the follow-up consisted of about 5-10 minutes meeting with the surgeon. That's it. I find it frustrating that they don't have the nephrologists meet with me, or a nutritionist, or social worker available for meaningful post-donation information. I mean, the surgeon knows about removing my organ and making sure I don't have a sponge left in me, or that my scar is healing well. But I don't feel confident in his ability to assess the functioning of my remaining kidney or to advise me on how to make sure I keep it functioning. As noted above, he didn't broach the issue of GFR or what my relatively high creatinine numbers meant or how I should eat or behave to best protect my remaining kidney. He just told me that he'd have me back for another check up in six more months, instead of the usual twelve month wait. I certainly hope that they schedule me to meet with the nephrologist rather than the surgeon for that one, and I'll certainly ask for that.

But, I did go and look at my medical records from the pre-donation evaluation. The nephrologist who assessed me put me in her text discussion at 0.9 creatinine (GFR around 75), and when I look at the lab reports, that is the lowest reading of all of them pre-donation. The rest of the readings range from 1.1 to 1.7. I've recently learned (NOT from my surgeon!) that there are different ways of measuring creatinine, so perhaps my higher numbers are of the type that the GFR calculators are not designed for, although I still wonder, because the lab lists the 'normal'

ranges on the same line as my actual reading, and for each of those the normal is listed as between 0.8 and 1.1. I will be discussing this with my own PCP, and with the nephrologists at the next follow-up (scheduled for 12 months from the donation).

Now, in terms of how I feel: I feel fine. I don't think I'm noticeably more tired than I was before donating (of course, I work full-time outside of the house in a high-pressure job and also am a wife and mother, so there is some level of 'always tired' that goes along with that...but not noticeably different from pre-donation!) I do try to make a more purposeful effort to drink more water, and I think that I feel dehydrated more easily – as if my body is telling me something! So, because I am not feeling any symptoms of reduced kidney function, I'm not particularly concerned about these creatinine numbers. I mostly find it frustrating as exemplary of the questionable 'informed consent' evaluation criteria and lack of appropriate follow-up and long-term data collection on donors. But, all in all, I feel very positive about the whole donation experience. It is a great thing to help someone in such a meaningful way. I do feel that I would do it again if I had more kidneys to spare, and I've recently signed up in the bone marrow registry.

Thanks for taking the time to read my story.