

## A Joyously Given Gift

### The Participants:

Julia, recipient, age 42; Gerard her husband, 17-yr old daughter Kate.

Susan, donor, age 59; Michael her husband.

Joan and Russ, parents of Juli, older sister and brother-in-law to Susan.

Ellen, aunt to Juli and younger sister of Susan; and Dave, Ellen's partner.

They provide support from their home in WI.

Wendy, aunt to Juli, youngest of the 4 sisters. Wendy and her family provide support from Am. Samoa and HI.

### Timeline:

2001: Juli is diagnosed with chronic tubulointerstitial nephritis, probably autoimmune, maybe due to Sjogren's syndrome. (Juli has dry eyes, but not enough other features of Sjogren's syndrome to be diagnosed with this.)

2004: Russ, Gerard, Ellen are tested for possible donation but are not highly compatible matches. Joan cannot donate due to recent breast cancer. Wendy's husband's family has a history of kidney disease, so she needs to save her kidneys.

9/2004: Susan begins the donation process with blood tests in Little Rock, AR. I have a completely negative crossmatch (a good thing), and a zero out of 6 antigen match (It would be better to have some matches. The negative crossmatch from mixing my blood with Juli's was considered a more important factor than the antigen matching.) A liver enzyme test shows 2 very high readings and is of concern to the doctors. A liver ultrasound and more blood analysis shows it to be, most likely, a transient phenomenon.

2/2005: Michael and Susan fly to New Haven for kidney scans, liver analysis, meetings with the social worker, surgeon, and coordinator.

3/2005: The surgery date is set for 3/24. Juli and Susan each get their preferred surgeon. This is an elective surgery, as Juli still has 10% use of her kidneys and has not been on dialysis.

3/19: Michael and Susan fly to CT.

3/21: Final tests and consultations with the surgeons.

3/23: Juli checks into Yale New Haven Hospital in the afternoon.

3/24, Susan is admitted at 6:30 a.m. and prepared for surgery.

3/26, Susan is discharged from the hospital by noon.

3/28, Juli is discharged in the afternoon.

I've included some observations below that I hope will be useful to other donors and recipients.

Right before surgery, I weighed about 190 lbs. I am 5'7" tall. I have an established program of swimming laps for 45 minutes 5 days a week, which I've been doing for about 3 years. I had started using a stationary bike for 15 minutes, 5 times a week, about 2 months prior to surgery. I am in general good health and have very accessible veins!

I read Ed Kadyszewski's report on the [transweb.org](http://transweb.org) site. Many of his testing and surgery experiences parallel mine. I did not, however, resume swimming and exercising until my incisions had completely healed, which was 3 weeks post-op.

Michael and I live in Little Rock, AR. All the bloodwork and associated testing was done through my family physician and the lab there. The extra tests that were needed to decide what was going on with my liver were also done in LR, through a GI's office and labs. All results were faxed to Yale for further analysis by the Clinic Team. It was sometimes frustrating getting the faxes sent and received in a timely manner, necessitating numerous phone calls and emails, from both ends of the process. At times it seemed that we would be held up indefinitely, but by February, everything finally came together. We all learned to have patience and to keep checking on progress. Juli and I kept each other aware of each email or phone conversation that took place. We let each other know right away if one of us found a quicker way to get information through the pipelines, or questions answered. The Yale team has a tremendous job to do. I could not have asked for a more caring, helpful and energetic group of people to assist all of us.

Juli, Michael and I arrived at the Center on 2/18 at 8:30 a.m., with books and iPod in hand for the waiting periods. (We even had sandwiches along, in case the schedule negated our having time to visit the cafeteria for lunch.) We signed in and were given "slips" for the lab work to be done 2 floors down, in the same Physician's Bldg. Juli and I gave numerous vials of blood and urine samples, directed by the highly efficient technicians. Within an hour we were both back on the 4th floor. Our schedule for the rest of the day included seeing my surgeon, meeting with my social worker (to make sure that I was fully responsible for making the decision to give my kidney to Juli, that there was no pressure in the decision-making process from anyone in either direction, and that I had a group of people to support me before and after the surgery). We did have time for lunch in the hospital cafeteria before the scan appointment.

They took CT scans of my kidneys — dye inserted thru my arm vein, which stung a little, then after the scans, a flush of saline (?) solution which also stung a little. If I am remembering correctly, when the dye went in, my torso got hot and I felt like I was peeing — of course I'd been forewarned by the technician. I drank copious quantities of water before the scan and had absolutely no after-effects.

We met with the transplant coordinator to summarize and answer any further questions. Juli was a wonderful guide through all of this. She is well acquainted with the physical environs and we wasted no time in searching for offices, cafeteria, restrooms. So, have a guide with you, or take some time to scout out the territory prior to the appointment day. Or, just ask. At Yale, if we had even a hint of a questioning look on our faces, we were asked if we needed help. What a great feeling!

We each carried a "portfolio" that included vital phone numbers, past test results, any information that we thought might be needed by the doctors or technicians. I had a copy of my EKG results from 9/2004. This information was not in my file at Yale. So, now they had a copy and an additional EKG was not required during the 2/2005 visit. An EKG was done on 3/21 as part of the final testing.

I found it very helpful to have Juli and Michael with me during the part of each visit that didn't need to be privately conducted between the doctor and me. Juli often had very pertinent questions to ask that I had not thought of. She also alerted me before the appointments, with ideas of things she knew I'd want to ask about, but might not have thought of myself. I had learned a lot from the internet, but she knew much more about the situation than I did.

We had been told that I might need to return to the Center on Mon. or Tues. if Friday's test results showed that further testing was needed. With this possibility in mind, we had planned our return flight to LR for Thursday. We phoned the Center on Monday and no further tests were needed, so we enjoyed the next few days visiting Juli's family and Michael's parents. We flew back to AR and waited a long 3 weeks for confirmation of the surgery date: March 24, 2005.

Michael and I flew to CT on 3/19. When Juli, Michael and I arrived at

the Clinic at 8:30 a.m. on 3/21, for the final tests prior to 3/24 surgery. I signed papers explaining the risks of this surgery, met with an anesthesiologist who walked me through that part of the surgery, signed preadmission and privacy policy papers, received insurance explanations. My surgeon explained the admission and surgery procedures. We all knew that there might be changes in the surgery procedures, and this was very carefully explained. (It might be necessary to switch from laparoscopic to open surgery, my lungs might be punctured and have to be reinflated, I might need a blood transfusion.) I truly appreciated being able to ask questions (with my written list in hand) and get answers. The doctors and clinicians always asked me "What questions do you have?" (not, "Do you have any questions?"). They were never in a rush. I could not have felt more cared for.

On 3/24, I arrived at the hospital with Michael and Joan and Russ. We were shown to a room, where my vital signs were taken, I donned a hospital robe, and within an hour of arrival was climbing up on a gurney for the ride down the hall to surgery. My identity and reason for being there was checked at every stage of the process. Each time I talked with someone, they identified themselves. In the hall outside the surgery room, I was told that I would be placed on the table and given a "cocktail". A tracheal tube would be inserted after I was asleep to administer the anesthesia. A catheter would be inserted, my abdominal cavity would be inflated, and I would probably have heavy gas pain upon recovering (I did not). I would have a pump to self-administer pain relief for the first 24 hours. I would awake in Recovery, and Juli would probably be wheeled by me upon her admittance to Recovery. The surgery would probably take about 4 hours total. I'm sure I was asked and told other things, but that is what I remember. All of these procedures had been explained to me by my surgeon, but this step-by-step explanation, as each stage of the process unfolded, was most helpful to me.

Gerard, Kate, Joan and Russ spent these hours in the surgery waiting room and the cafeteria. A monitor displayed patient names, location and time.

Each person reacts differently to post-surgery. I do not remember very much at all. I remember raising my arm when I was told Juli was there, and saying "Juli, we did it!". In reality, she was right next to me, and we were holding hands. I remember being told that I had

just given my kidney to Juli, and replying "I'm going to, but it hasn't happened yet." (Of course, it had and that was explained to me!) I do not remember leaving Recovery and being brought to my hospital room. I remember waking up and being asked if I was in pain and how much pain (from 1 to 10), having the pain pump explained to me again, having many visits from the nurses and doctors.

As many of us know from hospital visits, it is impossible to get more than 2 or 3 hours of uninterrupted sleep. Doctors come by on morning rounds, nurses arrive to check the IV, take vital signs, get you out of bed, empty the catheter bag, and care for your pain and nausea needs. I was fed ice chips for several hours after surgery. On Friday I received breakfast, lunch and dinner of hot tea, juices and jello.

Juli and I were across the hall from each other, in private rooms. She visited me on her first walk, on Friday morning. Michael, Joan and Russ, Gerard and Kate, all visited us at various times. At least one of them was in either Juli's or my room most of the time for 2 days. They had more interaction with Juli, as I apparently spent most of my time asleep!

I had a lot of nausea due to the pain medications (a non-codeine morphine-type drug and Percocet), and in getting the anesthetics out of my system (what a vibrant green it was!). The anti-nausea drug used 3 times was not effective. A different drug was used after this and was effective. My sister Joan and I should have been more assertive in asking for a different drug sooner. Joan raised the question but the nurse decided to use the same drug. I was not thinking very clearly at that point. It was too easy to let things slide, even though I was not feeling well. So, speak up, have an advocate with you, and encourage that person to be pro-active concerning your needs. The nurses do a great job, but we do need to raise questions at times.

After I was discharged from the hospital, Michael and I continued staying at the New Haven Hotel, walking the 5 blocks to visit Juli, walking to some of the great restaurants that New Haven offers and around Yale to sightsee. My need for sleep continued, but I was never in any pain. Even turning over in bed was not painful, just uncomfortable feeling around the three 1-inch and the one 3-inch incisions.

What an added thrill it was to visit Juli at her home, and feel the outline of my kidney, just under her skin on the right side of her

belly! I think it was at that moment that I fully realized that she had one of my kidneys.

I had follow-up appointments at the Center on 3/30 and 4/8. It took about an hour or two for my blood and urine test results to reach the Clinic area, then I met with a nurse and a doctor. I was told to continue drinking a lot of water.

My serum creatinine (Yale's reference range is 0.5 to 1.2/mg/dL) was 1.4 on 3/26; 1.3 on 3/30; 1.2 on 4/8. Pre-surgery normal for me was 0.9 mg/dL or less. I've given these readings because this seems to be the main test to indicate kidney function.

After my 4/8 appointment, I was told to have my family physician in Little Rock do a blood creatinine test, a test for protein in my urine, and the usual blood pressure (in both arms) and other vital signs. He would fax the results to the Center. If I had any questions, I was to phone or email my surgeon. I have had questions and Dr. Sanjay Kulkarni and the transplant coordinator have quickly answered them.

I had these tests done at Dr. Watson's on 4/14 and will repeat the tests on 5/24. After that, unless any problems develop, I will be considered completely healed and ready for my next adventure, whatever that may be!

This entire experience has been a completely positive one for me. I had not even an inkling of a doubt that this was what I wanted to do for Juli. (I had been in the hospital for 2 back surgeries in the 1970's, and so was somewhat familiar with hospital procedure, though much has been improved since that time.) I feel that it is really our entire family giving her this kidney, I just happen to be the person who had the best actual kidney to give her. It will probably be many months before I stop extolling the benefits of kidney donation. If even one person with whom I talk decides to offer their kidney to someone in need, all my words will be worth the effort.

Juli, may you live a long, happy and productive life with your new kidney. Love from Susie.