

My Story as a Living Donor Kidney Recipient

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Ok, I am not a blogger but....but what I am is a kidney transplant survivor, and I will be making my first appearance at the US Transplant Games in Madison, WI at the end of July. I told my story last week to an LT HR team and people asked if I would write about the games. I figure I will provide some context as to how I got here in the first place and we'll see how this goes. I will do a separate blog for the Transplant Games.

Not everyone has the opportunity to say they have a birthday and a rebirth day. My rebirth day is Nov 5/08 -- that's the day I received an amazing gift from a long-time girlfriend -- a new kidney. I was born with polycystic kidney disease (PKD). It's genetic and causes slow deterioration of one's kidney function over time due to cysts enlarging. There is currently no cure so I knew I would be faced with either dialysis (likely) or a transplant (rare). So I know I'm extremely fortunate as I received the latter -- a gift that I will never be able to properly say 'thank you' for.

I saw my mother begin dialysis when I was 10 years old. The machine terrified me -- the 12 inch needles, watching her blood filter through a machine, seeing how sick she was even after treatment. As I grew older, I began to understand the impact it would have on my quality of life. I found out I had PKD when I was 20 and the adult type I have typically doesn't affect one until in 50-60's. In my early 30's, my function was under 50% so I created what is now affectionately termed as my 'bucket list'. I saw and did things I thought I may never do again if I was dependent on a machine 3 times a week to keep me alive. I traveled to 22 countries; I skydived, I climbed Mt Whitney, Macchu Picchu, Kilimanjaro; ran 5 marathons and a dozen half marathons; learned how to kayak, downhill ski, sail; got my MBA to position myself to do part-time work in the event I could not work full time. I lived life -- it wasn't pessimistic but pragmatic cause I knew what lay ahead in my future.

While I couldn't control what was happening to my kidney function, I could influence how I dealt with the disease through diet and exercise, so I looked after myself. I followed a renal diet which is low potassium, sodium and protein. But by the fall of 2007, I had hit the 20% function mark which enabled me to get on the US Organ Transplant list to begin earning time so that when I really needed one, I would be close to the top of the list. By the spring of 2008, I was at 15% and my routine was sleep for 10 hours, work for 8, get home sleep for 1-2 hours, get up to eat, go back to bed and sleep. I continue to run, actually shuffle would be a better description as it took everything to get in 1-2 miles. I was anemic, cold all the time -- sleeping under a winter duvet when it was 85F and still shivering. I began to have a metallic taste in my mouth due to the waste in my blood so I had to force myself to eat though I had no appetite. I

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frequently would get leg cramps lasting 1-2 mins which I couldn't do anything about. I had a constant foggy feeling in my head that didn't allow me to think clearly. My eyes and skin were beginning to yellow.

By this time my nephrologist (kidney doctor) told me if I had anyone interested in being a living donor, now was the time. So how do you exactly tell someone "hey, wanna give me your kidney?". It's awkward and it's hard to ask for that type of help. My close friends saw the deterioration and I began to get approached by different friends – 6 in all, which was humbling in its own right. I think the hardest part was the waiting. I give the people's names to UCSD and then there is no contact. As a living donor, you have the right of refusal up to the day of surgery. It is not only physical compatibility but also emotional and psychological. So I waited and in mid August, I had another friend approach me so I contacted UCSD to arrange paperwork. I clearly remember the day Aug 18 because they told me they were not going to test anyone because they found the perfect match. I was told that she had more test but the match was like we were siblings. So my mind raced as I ruled out my 2 male friends. So I continued talking to try to figure out who the "she" was and they were just so excited they blurted out 'it's Conna Jones and it's like you were sisters. But we really weren't suppose to tell you and she has a final test to do as part of the routine'. Since I had no idea where she had been doing her tests, I asked if it was at UCLA or UCSD and was told 'it would be very easy for you to see her on Mon'. Tears started rolling down my face as I ended the call and immediately called Conna.

Now I need to take a few minutes to tell you about Conna – she is simply amazing. I met Conna 19 years ago sharing a office at a real estate company in Calgary, AB. She loves life and has the most infectious smile I have ever seen. We both had grown up in small town Saskatchewan, Canada about 3 hours apart. She apparently played volleyball against my high school. We became fast friends over the 7 years we lived in Calgary. I then moved to Vancouver, BC and a year later she moved to Nanaimo on Vancouver Island so we were able to reconnect via ferry and float plane rides across the Georgia Strait. Then eight years ago, I moved to San Diego and a year later, she moved to Fullerton in Orange County to be with her now husband, making us neighbors once again. As long as I had known Conna, she wanted to be a mom so she began with 3 step-children and then she had her own baby boy Jake. It was a difficult pregnancy and a hard labor with complications resulting in him being born 2 months pre-mature in Jan 2008. He had to be in pre-natal care for the first month which was the hardest part for Conna. This is key to the story.

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So getting back to finding out she was my match – I called her up and told her I just talked to UCSD and they spilled the beans. She replied “I am so glad you finally know. I’ve been avoiding you all summer because I knew I would blow it and tell you things were looking great. Ok, so I’ve talked to my family and it’s all arranged. If you can hang in there for a couple more months, we can do this the first week of November, that would work best. Scott will be home and my mom will come down from Canada to help look after Jake (who would have been on 11 months old). All you have to do is say yes”.

My immediate response was “As long as I’ve known you, you’ve wanted to be a mom. You just had a baby and I would never forgive myself if something happened to you. You also just had traumatic surgery yourself” Conna replied “It’s meant to be – that’s why I’ve been following you around all these years. If I can help you avoid going on dialysis, I’m going to do it. I felt so helpless when I didn’t know if Jake was going to live and the St Jude staff were so caring to my son. I want you to live again and it pains me to see you so sick when I can do something about it. I only need 1 kidney and it's not a big deal. This is a way of helping you and also for me to pay it forward.”

We cried again and then I met her that Monday during her final tests and of course more tears flowed. I still had reservations but she was so confident and so committed. The good thing about living donation is that you can plan it and being a project manager, that’s right up my alley. The other friends who offered to get tested asked how they could help so I arranged an international assembly of friends from Canada and Europe to fly in for one week stints since I would need people to be with me, take me to appointments, etc. The support was phenomenal from people who stayed with me to past co-workers arranging a meal drop schedule every couple of days for the first month.

The worst part was the waiting – we had Nov 5/08 booked but all the anxiety that goes through one’s head is hard to control. What if something did happen to Conna? How would I deal with that? What if it didn’t work and I was forced to go on dialysis? I hated that option with a passion – I knew it would keep me alive but it wasn’t living in my opinion and there was a period where if that was my option, I would rather not live. And then there was a very small part that thought -- what if I die? What are the meds going to be like? Will I ever run again post transplant?

Our surgery date couldn’t come soon enough but it eventually did. John described this in his donor story but it also was true for me – the immediate first words I wanted to hear upon recovery was ‘Is Conna ok?’ So we both arrived at 6am, she went into

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surgery first and I followed an hour later. I remember waking up and asking my question. I was told "yes she's fine". I however had a lot of pain and there was a lot of activity around me and was then told "something's wrong with you though and it's not connected properly. They need to take you back into surgery". Now my mind is racing wondering if the kidney was rejecting. I was assured the kidney was fine but the artery was kinked and they needed to fix that. So while my initial surgery should have taken 4 hours, I was in for 5 and then went back in for another 5 hours. I don't really remember much other than being wheeled around a lot as I was in and out of consciousness -- and being simply terrified. I woke up around midnight and was told the 2nd surgery was successful. The kidney is big and my frame is small so they cut fascia to make it fit. The next morning Conna was brought down to see me – she knew at that time, I had problems so we both started to cry and then laugh. But laughing or coughing is so very painful that she was there for a couple mins then had to leave so it hurt us both too much.

One my first day, I extracted 9 liters of urine – that's A LOT of pee! But it was a great sign that the kidney was working because some transplants it doesn't right away. I immediately noticed the disappearance of the metallic taste and actually wasn't cold anymore. I had color in my skin again. I was forced up to walk that Day 1 to help with the recovery. I ended up in the hospital for 8 days due to my complications but Conna went home on Day 2 (Day 0 is surgery day). The pills were overwhelming as I had 3 immunosuppressant (Prograf, CellCept and Prednisone) and then several drugs to counter the meds, some you take with food and others you don't and the anti-rejection meds need to be 12 hours apart. I had to learn to give myself insulin shots. I took strong antibiotics to ensure I wouldn't get infection but that upset my stomach so I took an antacid. One drug made my magnesium go down so I had to take a supplement for that. I was on high blood pressure medication and also pain meds. At the beginning, the dosages are so high that blood and urine samples are taken several times a day. The drugs had other side affects like crying periods for no reason, hand tremors, not sleeping more than 2-3 hours. Add to the body trauma, hemorrhoids and my cycle started – what else?!! But I was alive and not on dialysis and that's all that mattered. When I left for home, I was provided a shopping bag full for 1 month with over 13 meds taking 33 pills a day long with insulin shots. How am I ever going to remember all this?

For the first month, I was at UCSD 4 times a week – twice for labs and twice for follow-up appointment to adjust my meds. I couldn't drive, still wasn't sleeping well but I was

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walking up a couple miles by the end of the first month. The checkups then went to 2 times a week and then down to once. I was with UCSD for 3 months before being transferred back to my nephrologist. Now given my background, I wanted to know how I could get off as many of the meds as possible. I always have to be on immunosuppressant meds because my body will always want to reject it. But you want the lowest dosages possible because ironically Prograf slowly poisons the kidney. So I worked with dieticians to find ways to adjust my diet – I cut out a lot of sugar so I could stop the insulin shots. I began to exercise again and meditate so I could get off the blood pressure medication. By my 5th month, I was down to minimum dosages of my 3 anti-rejection meds and vitamin supplements. My doctors told me that wasn't normal and they weren't used to dealing with a "healthy patient". I had started to slowly run again but the cutting of the fascia caused pain in my right leg. The kidney was herniated from the original surgeries to the point that I could cup it in my hand in my lower abdomen. I was told it was protected but I had to give up sports unless I wanted surgery again. I opted for the surgery and underwent a repair where they went back in and secured the kidney with strattice mesh. That was Jun 1/09 and was told to not do anything for 6 months. The toughest pill I had to swallow. Just when I got the ok to get back exercising in early Nov, I had a bone scan and due to Prednisone, the bone density in my spine and hips was close to osteoporosis. I remember asking how could a drug have that affect in only 1 year? It just does with some patients. So now I take Fosamax which has its own controversial aspects but I am trying to regain some bone loss but unfortunately, always have to be on Prednisone. I do have an advantage of being a runner so between that and doing strength training, I can at least balance the effects of these drugs but will never regain the bone loss.

I feel fantastic today and am currently back up to a 5km and training for sprint triathlons which are short in distance but enable me to race and feel normal again. My med routine hasn't changed much – I take Prograf at 6am and 6pm on an empty stomach which means typically no food for 2 hours before and 1 hour after. Not bad for the mornings but harder in the afternoon, especially if I am trying to get a workout in the evening. Then the remaining 2 anti-rejection meds at 7am and 7pm with food. I will never sleep in again. I'm paranoid about throwing up because if I do as a result of a flu or riding too many rides on at an amusement park (which yes has happened), I go to emergency because I need the meds intravenously. I have traveled internationally again which is getting more comfortable but it does mean I have to adjust my meds and know where the nearest hospital is just in case. My immune system is very suppressed so a common cold can take me 3 weeks to get over and I do get paranoid a

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bit when I'm sitting by someone who is sick. But those are still minor items to have to deal with given I have my life back.

Conna is also doing great -- Jake is now 2 1/2 and the healthiest little boy. She tells me she forgets it even happened until I am talking to her. Our relationship is even stronger and I do believe we are soul sisters. I've been able to do events with her like decorate the Donate Life float for the Rose Bowl, get her involved in donor education panels at UCSD and we ran/walked our first 5km race at a Donate Life event in May. I arrange for she, John and I to meet which was fantastic on so many levels. It was rather amusing as we sat at the table -- she and John with only 1 kidney, Jake with 2 and me with 3!

I have way more to share but this is likely more than enough for now. I want to share my story for a few reasons – to illustrate that when one is faced with adversity, a positive attitude is everything. Wellness and healthy lifestyles can make a huge difference even when faced with an illness. Most importantly, until we find cures to these illnesses, or alternate stem cell therapies, organ donation saves lives, and in the event of a kidney, liver or bone marrow transplant, it allows someone to truly live a normal life again. Whether it is living or after you have passed, one can truly give life back to a fellow human being - that is incredibly powerful and the most amazing gift you could ever provide.