

## **My First USA Transplant Games**

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So I mentioned in my transplant post, that I will be making my first appearance at the US Transplant Games in Madison, WI at the end of July. This is huge for me and I'll tell you why.

In my other post, I mentioned I had my bucket list and qualifying for the Boston marathon was on my list. Perhaps to most, marathons are an extreme mode for keeping fit, but it was just as much a mental challenge for what lay ahead in my future, as it was physical. My best marathon was 5 mins away from qualifying for Boston - I was so bummed! My last marathon was my worst taking just over 5 hours in 2007. But I have an excuse because at that time I had 18% kidney function left. I was feeling quite sick by then and walked a lot in that race. Every time I wanted to quit, I told myself "this is the same amount of time it will take to do one (1) dialysis treatment. And if Mom endured dialysis for 10 years and it's as hard as this, so can I...so suck it up!" By early 2008, I could barely plod 2 miles as I dropped to under 15% function. I was very anemic and all I wanted to do was sleep but I forced myself to shuffle along just to keep me sane.

It is understatement to say that my life changed a complete 360 after my transplant. The recovery hasn't been easy though -- my frame is small and the kidney was nice and healthy so I had to undergo 3 surgeries to get it to fit properly in a period of 12 months. You don't realize how much you rely on your abdominal muscles to basically do everything. My last surgery was 1 year ago and I got the clearance to exercise in Nov/09. With the help of fantastic trainers, I learned how to run from scratch -- 1 min run, 2 min walk, 7 reps. Now for someone who has run 26.2 miles multiple times, this was incredibly frustrating but I knew I was on my way and each week I could see myself make progress, small progress, but it was progress.

By Apr of this year, I completed my first 5km race in 28:10 -- what an incredible achievement! I knew I couldn't ramp up too fast so I figured I would start sprint triathlons. Always wanted to do one, and like most, my swimming needs help. Abdominal surgery doesn't help my swimming either but I'm making progress. Sprint tri's would give me the ability to learn something new, and race again. I wasn't sure if I would be ready for the Transplant Games but 3 days before the cutoff in mid-May, I registered cause I'm one of those people who likes a goal and likes a challenge.

Between Jul 30-Aug 4, I am going to be competing in a sprint triathlon and 1500m race as part of the Southern California team. I am more excited to know that everyone I compete against has had 1 or more organ or tissue transplants. The most frustrating aspect of my journey is the medical teams not really knowing what to do with "healthy"

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patients. So for me, this isn't just about the chance to race and win a medal, it's about proving one can regain a normal, athletic life after transplant. They also do a huge celebration to honor both living and deceased donors so my donor Conna will also be running a 5km and will get to be honored in a Living Donor celebration.

These games illustrate one can race again post-transplant. Actually, it's more than that -- there is nothing one cannot overcome if you have tenacity and determination. Anything is possible....like getting a second chance at one's bucket list. Maybe Boston can go back on the list after all.

I do have a personal page for the Games with proceeds go to supporting the games and sponsoring donor families to attend. If you want to contribute, the link is here <http://donate.kidney.org/goto/louiserocks>.

Need to get some rest now -- have a 5km run and swim workout to do in the morning

## **June 28 - 33 sleeps til the games**

Switching from running to triathlons is what they call a lifestyle change...and it is so true. No longer can I just throw my running shoes into the car, but now need to figure out the logistics of finding a pool or open water, learning how to swim, and getting seat time & miles on the bike. This is a challenge for most who take up triathlons but also working around a med schedule and diet restrictions adds a few more factors most don't think about. I have limit my salt and potassium even post-transplant so cramping is more common than most, and I can't eat 2 hours before 7am or 7pm so finding a way to get energy before a workout is not the easiest. But like most things thrown my way, I don't let that deter me.

So on to training – I have the advantage of having run many races so that part is easy. The not so easy part was dealing with the cramp in my right quad. My new kidney is connected to the artery in my right leg and for probably the first 6 months, I experienced pain initially then discomfort forcing me to stop. I have run through a lot of pain during marathons but this was a different pain and one I knew I couldn't, nor shouldn't, run through. It's subsided mostly now if I stay under 5km but it has been an unfamiliar feeling that my doctors and massage therapists cannot explain.

Swimming – I grew up learning how to tread water and not drown in the local lakes. To say swimming is my weakness is a gross understatement. Trying to efficiently swim 25m let alone 500m has been hard. And when one has had abdominal muscles cut via a 10 inch incision reopened 2 times, trying to keep my core parallel is not the easiest

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thing to do, even in the water. For the games, the swim is in a pool so I unfortunately don't get the benefit of my buoyant triathlon wetsuit to keep my legs up. A couple times a week I get up at 5am and do 30 mins of laps and then I have a 1 hour lesson Thu evenings. My swim coach is a ex-pro triathlete and actually has worked with a kidney transplant recipient before. Finding coaches that understand the recovery I am dealing with is huge.

Now for the bike, much easier to deal with as it is a little more natural for me, but my biggest fear was falling. I started off with 10 miles rides and most weekends now I get in usually two 15-25 mile rides and then another ride or spin workout mid week. For the race, I need to do 12.5 miles. The challenge I have with the bike is hills. I take much shorter breathes post-transplant and not sure if that will ever go back to normal so it's harder for me to get oxygen. I often wear a heart rate monitor to ensure I don't over-exert myself because a high heart rate is less noticeable on the bike for me, than a swim or a run.

I was quite scared to get back on my bike post-transplant because I ride a road bike and use clipless pedals (for those not familiar, the bottom of my shoes are clipped into my pedals). This makes riding more efficient but it also makes it much easier to fall with your bike. On the first easy, flat ride in Mar/09 post-transplant, I had to make a sudden move and couldn't unclip in time. I knew I was going to fall and all I kept saying to myself was "fall on your left, fall your left, protect the new kidney on the right". But I fell on my right, laid on the ground for a little while before unclipping, and then got up. I wasn't sure what to expect so I felt around my kidney, saw no blood, collected my thoughts and rode 4 miles back home. I called my doctors to tell them what happened, and they assured me it was well protected and unless there was pain, I didn't do anything to harm it. I put the bike in the garage and didn't ride it for the rest of the year.

When I decided in Jan of this year to learn how to do sprint triathlons, I knew I had to overcome my fear of the bike. I started riding easy again in February, and then along the 101 Coast Highway which I've always wanted to do. It's a gorgeous route but a very busy, narrow road for cyclists. You need to be alert of cars and be prepared to unclip at any second. Some people think this is crazy but I guess I like to face fears head on. The pinnacle for the 101 for me though was the 1.5 mile Torrey Pines hill – it's long, has some good grade and was intimidating. With the encouragement of my girlfriend Karen, I've been up it now a few times.

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Yesterday, we decided to go up Point Loma to the Cabrillo Monument and down to the tide pools for a different steeper hill workout. While still in the parking lot getting ready to ride, I went to turn my watch on and promptly fell over forgetting I was clipped in. I fell yet again on my right. I ended up breaking some of the fall with my right shoulder and have a some scrapes and bruises on my left shin as I was attempting to clip out. It was such a classic yet stupid fall! And while my confidence and pride was shaken up a bit, this time I felt better knowing my kidney was ok. We proceeded to ride 11.5 miles and conquered a new set of hills. It was a slog for me but I actually did it without stopping – woohoo!

Today's workout – did 25 mins of swim laps at 5:30am this morning and tonight I have a 1 hour strength training session. Another great trainer was connected with me – she too has polycystic kidney disease (PKD) so she has helped me with my recovery and supplement recommendations that don't interact with my immunosuppressant meds. In turn, I've shared my transplant experience, which she likely one day will need. Last year we worked on getting movement in my core again. It took me 5 months to sit upright from a flat position without using my hands or feeling pain. The good thing is that the herniation repair surgery last June has made a huge improvement in the range of motion in my abdomen this year. There are still some bends I can't yet do....but it's like running where I look at a long range goal.

The other purpose of my weight sessions is to work on strengthening my spine and hips to attempt to counter the negative bone density effects of Prednisone. I find it ironic that while on the outside, I can see myself become stronger; on the inside, I have a daily life-dependent anti-rejection drug working against everything I am doing. I can only hope to sustain and not further progress the negative bone density status. It doesn't seem fair and some days I get angry, but I know things could be worse....at least I can exercise again.