

The Swope's and Roger's Polycystic Kidney Disease

Polycystic Kidney Disease or PKD is an inherited disease. One or both of your parents had the disease for you to have it. If only one of your parents have the disease, then there is a 50% chance that you do not have the disease. The best way to diagnose the disease is to have a sonogram after you reach your 20's. If the sonogram shows you do not have PKD, then you will not have it and will not pass it on to your children. If it shows you do have it, then there is a 50% chance that your children will get PKD, but also, a 50% chance that they will not. A Nephrologist will be able to help you with this, also, a genetic counselor.

My mother had PKD; most of my life I have known that she had it. Her father, my grandfather, had the disease and died of complications from the disease. That was in the early '70s. My mother was on dialysis since April of 1982 until she died in September of 2000. She was on peritoneal dialysis, CAPD, and her sister (my aunt) got a kidney transplant in November 1988. Her brother, Dan (my uncle), was on hemo dialysis and did receive a transplant later.

In Oct of 1998, my aunt's body started rejecting her kidney. She had the kidney almost 10 years. She is back on a kidney list and will probably be put on dialysis soon. This was very sad news coming right before my sister's and my transplant/donor surgeries.

I am 47 years old and do not have PKD. My sister (Karen) does. She is on a list hoping for a kidney and is not currently on dialysis. I have undergone testing to give her one of my kidneys. The operations are scheduled for November 3rd. There is a chance that a kidney will be found for her before that, as she is on a list and wears a beeper. (The kidney was not found and the operation with my sister and I was successful.)

The worst test was the renal arteriogram. The doctor makes a small slit at the very top of the leg at the groin and threads a tube up into the artery to inject dye in the kidneys. They then take x-rays to see how many veins and arteries the kidney has. That way, when the doctor goes to remove the kidney, they know what to expect. The hardest part about the test was after the test you have to lie flat on your back for 6 to 8 hours. During that time they are giving you fluids by IV trying to flush out the dye they used during the test. They do not put in a catheter, so that means you have to use a bed pan. Have you ever tried urinating while flat on your back? It is not easy and it is not fun. I was very lucky that my other sister (Vicki) went with me. The nurses are very busy with sick people and couldn't stand around waiting for me to use the bed pan. Vicki helped a lot!! I was very glad she was there.

During all the testing, I think they took about 50% of my blood and enough urine to fill a lake. ;-)

The next step is the operation. November 3, 1998. As the time gets closer, I'm having so many emotions I can't really define. It's hard to accept that they have tested me for everything under the sun to find me completely healthy, and they are going to operate on me anyway. (All was a success.)

I train horses for a living, so my life is an active one. I don't look forward to the recuperation period where I'll be hurting and then the time I can't work my horses.

November 30, 1998 Monday

Received news that our aunt died of a heart attack. She had a heart attack a few years ago and they had operated then. Last night she had another and passed. We are all sad.

December 1999

The Athen's Newspaper has called wanting to do a story on the "year anniversary" of our operation. Karen and I are both doing great. Karen has had no real problems at all. She is healthy and happy. Married now and she is enjoying being with her kids again. Before, it was tiring her out so. She has lots of energy now.

January 30, 2000 Sunday

A call has come in that my Mother's brother, Dan Rogers, is going to get a kidney. He went through the operation and was back in his room at 12:30pm on Sunday afternoon. That night, they had him sitting up on the side of his bed. What good news this is!!!

May 7, 2000

Dan Rogers is doing great! Karen is on 6 mg of prednisone and doing wonderful. At the end of the month she will be on 5mg. Her creatinine 0.9, which is really low. At 4.0 they start you on dialysis. She is on Neoral at 125mg twice a day (which is very expensive), and Cellcept at 500mg twice a day. PKD gives you high blood pressure, so she is on medication for that also.

Karen and her husband have custody of his kids, they have five now, and Karen is able to enjoy all the kids.

I don't miss the kidney and my life is full.

April 2001

Dan Rogers is still doing great. He had some problems with diabetes for a little while, but I think they have that under control.

Karen and all the kids are doing great. They keep cutting back on Karen's med's. She's taking less and less all the time.

2017

Next year will be our 20th anniversary of the kidney operation. Karen is still doing great! Found out one of her kids (Megan) has PKD. I'm doing fine, still working and riding horses, and will close this dialog out.