

Combined liver and kidney transplantation

Dear Readers,

my name is Theresa Hermann, I am 21 years old and have had the disease Primary Hyperoxaluria Type 1 since birth.

In the following I would like to tell you how I was and what I experienced in the time before, during and also after my combined liver-kidney transplantation.

My transplantation took place in the night between 19 and 20 October 2012. Before the procedure, which changed my life, I had to undergo hemodialysis 3 times a week for 4 to 5 hours. As I was still attending a grammar school at that time, I missed a lot of school hours, which I had to make up for by working on my own - mostly on weekends.

Now the question arose almost automatically, when I would be "listed", since I am young and did not want to and could not stay on dialysis forever. A longer dialysis time would have meant that more and more oxalate would have been deposited in my body during my basic illness and this would have impaired the success of the transplantation.

I first had myself "listed" in Heidelberg (2011). I continued to be treated by my nephrologist, Professor Hoppe in Cologne. Less than a year later, i.e. 2 to 3 months before my transplantation, I decided to "listen" in Bonn after all. I very quickly gained confidence in my local surgeon, Dr. Pollok, and felt that I was in good hands, which was one of the main reasons why I changed my transplant centre. In addition, Prof. Hoppe was now working in Bonn. Also during my time after the transplantation in the hospital and later in the post-transplantation care I was very well looked after by my medical team, which was there for me and took care of me all the time, day and night.

I spent the first 2.5 weeks after the transplantation in the intensive care unit of the Bonn University Hospital. I lay in a single room with many beeping machines around me, to which I was connected by a central venous catheter. Through a small "stent" in my arm artery, pulse, temperature, etc. were permanently monitored. My new liver had started working again immediately after its implantation, the kidney, however, "mourned" for quite a while and only started working after about 4 weeks. For this reason I was still dialyzed after the transplantation.

However, a bigger problem at first was the danger of pneumonia. Because of the long lying during the transplantation, which lasted about 12 hours, and the many infusions, an enormous amount of water accumulated in my entire body (after the operation I weighed almost 10 kg more). Through machines and other, smaller operations the water could be slowly removed.

The days in bed and the resulting lack of exercise caused my muscles to deteriorate very quickly. Together with physiotherapists I practiced getting up, walking and standing, did breathing exercises and tried to rebuild my body through daily exercises as far as the tubes - with which I was still connected - allowed.

Every day I was examined, monitored and visited by my doctors.

When my physical condition had stabilised somewhat and was slowly improving, I was allowed to switch to the normal ward. While I tried to get back on my feet, to move, to regain strength, I was still waiting for my kidney to "start". When after another 2 weeks the time had come, I was finally

allowed to go home after a few more days of supervision, 1 month after my transplantation in October!

The first time at home was very difficult for me. Although I was very happy to be back in familiar surroundings, it also required a lot of strength and energy to cope with my everyday life. Physically I was always quickly exhausted and had problems taking the huge amount of medication (about 40 pieces per day), especially in the beginning. With time, however, these became less and less. In the first months after the transplantation I often had to stay in Bonn because of high fever, infections, ...etc.

After about 5 weeks in hospital and 2 weeks at home I went back to school. Of course with mouth guard! Which I wore for the rest of my school time -6 to 7 months. After 2 to 3 months after the transplantation I was allowed to participate actively in sports lessons again and had no pain or problems. Like all my classmates, I completed my high school graduation in July 2013, and in the following November (2013) I was able to catch up on a 6-week rehab, which rebuilt me physically and mentally, trained my endurance and put my metabolic cycles into perspective.

Since the beginning of 2014, all my blood values have improved, so that I so my health related values are now firmly in the green zone. Because of this, since this year I don't have to go to Bonn so often for aftercare examinations, at the beginning it was almost weekly visits to the university hospital Bonn, now it is 3 to 4 aftercare examinations per year. At the moment I feel very well! I feel well, I am balanced and fit enough to be able to start my studies next fall for the winter semester 2014/2015.

On the following link you will also find an interview of me, which "Nephro TV" recorded during and after my stay in hospital after the transplantation in Bonn:

<http://www.animaniacs.de/wordpress/2014/02/17/portrait-theresa/>