

## Crossover living kidney donation for two patients with cystic kidneys



(From left to right) In front: Lothar Merk, Maria Merk, Elisabeth Woitzik, Franz Bergen. Behind: OA Dr. Lutz Liefeldt, OA Prof. Dr. Robert Öllinger, OÄ PD Dr. Mira Choi, Prof. Dr. Frank Friedersdorff, Prof. Dr. Klemens Budde ©Matthias Krüger

Dialysis patients wait an average of eight to nine years for a cadaver kidney donation (from a deceased-donor). Unfortunately, during this waiting period many people on the waiting list die.

An option to shorten this waiting period is through a process known as living kidney donation. Not only can the waiting time be reduced, but in most cases the transplanted kidney is actually more efficient and can function longer than a cadaver organ; a great advantage for kidney recipients.

A now 24-year-old transplantation law has imposed many formalities on living donations, which has resulted in a very scrutinous examination process that limits the opportunity for many people to receive a crossover living kidney donation (a special type of living transplant). Often, these examinations bring all those involved – the recipient, the donor, the medical professionals, and the members of the living donation ethics committees

– into unpleasant and sometimes inappropriate situations.

The following account is of our crossover transplantation, which was successfully completed in October 2021 at the Mitte and Virchow campuses of the Charité Hospital, in Berlin. In the following sections we recount our own hurdles and hopes over six years of dialysis and during the three years of organization leading up to this successful transplantation.

### Cologne: Elisabeth and Franz

After four years of peritoneal dialysis because of cystic kidneys caused by an inherited disorder, I, Elisabeth, wished finally for a healthy kidney and a normal life. My husband Holger offered me his kidney; however, crossmatch results showed that he was positive for destructive antibodies and therefore deemed ineligible to donate to me. Immediately after my friend Franz, whom I have known for 50 years, offered me his kidney. This time the crossmatch indicated that a transplantation was possible, but only after I underwent immunoadsorption (= targeted removal of auto-antibodies). However, the immunoadsorption processed failed at the final stage. Thankfully Franz's willingness to donate his kidney for me persisted and he agreed to be a crossover living donor to a couple who were in a similar situation to ourselves, Maria and Lothar. Franz was a match to Maria and I received from her husband Lothar a kidney that matched my blood- and tissue-type.

Until the transplantation, Franz and I had a long road with many bumps and seemingly hopeless situations. In retrospect, however, it was precisely these situations that gave us the decisive impetus to continue. One should never despair in the face of obstacles.

### Biberach an der Riß: Lothar and Maria

My wife Maria knew for a long time that she had inherited cystic kidneys disease, which forced her to undergo dialysis therapy in July 2020.

As her husband, it soon became clear to me that only my living kidney donation could bring a way out of her having to go for this life-shortening, permanent therapy.

On our own initiative, we inquired in detail about this procedure at the University Hospital in Freiburg and soon received an appointment for the necessary blood crossmatch and discussion with the medical staff.

While we were eagerly awaiting the results of the blood tests, it became necessary for my wife to undergo surgery to insert a Demers catheter (= atrial catheter) for dialysis treatments.

Shortly thereafter, we also learned that due to the antibodies of my wife Maria, I was not eligible as a direct kidney donor because of there being too high of a risk of rejection.

There is almost always another chance.

I had the nearly impossible luck of finding a second person in my close circle who was willing to donate his kidney to me, after my husband Holger could not, due to incompatibility. Franz knew of my problem and had been thinking about donating to me for some time. When he heard about Holger's and my crossmatch results during a joint game evening, he offered me his kidney.

Within a very short time, I made the necessary appointments to go through the crossmatch tests with Franz as well. The results, despite a blood group difference, showed a much higher chance that my body would not reject his kidney.

The meeting with the ethics committee, in which he, as a non-relative, had to explain his personal relationship to me, took less than ten minutes before he was cleared for donation and transplantation.

After that the surgical preparations could begin. However, before surgery, immunoadsorption was necessary. Unfortunately, this failed to remove the autoantibodies and immune complexes that could have led to antibody-mediated rejection of the donor kidney. The surgery had to be canceled.

Following advice from my dialysis nurse, I searched the Internet for information about crossover living donations. I found the contact details of Susanne Reitmaier ([www.crossover-nierenspenderliste.de](http://www.crossover-nierenspenderliste.de)) from Wolfsburg. On the same day, I contacted her by phone after asking my two donors about their willingness to participate. With the data sent, Mrs. Reitmaier and mathematician Dr. Agnes Cseh, compared our data to others from a pool of participants. After only two months, I received the positive news that a matching couple from Baden-Württemberg had been found.

I remembered an article in the professional journal „DIATRA“, which I had taken with me from the University Hospital in Freiburg. In it, a similar case was described in which a young woman was helped by a crossover living kidney donation.

We were thrown a lifeline by Susanne Reitmaier, the mother of that young women that received the crossover living kidney donation. Ms. Reitmaier's great commitment to this cause led her to found the organization CROSSOVER-NIERENSPENDERLISTE (CROSSOVER-KIDNEY DONATION LIST), through which many donor-recipient couples can be helped when it is not possible to make a direct organ donation between them.

We immediately contacted her in Wolfsburg and quickly received the help we had been hoping for.

With the help of Dr. Agnes Cseh, an expert in matching algorithms, we reported our laboratory results and within two weeks received the name of a pair from Cologne, which, after evaluation of all laboratory data, should be a perfect genetic match for us.

My values matched those of Elisabeth, who became the potential recipient of my kidney. The values of her childhood friend Franz matched the values of my wife Maria, who thus also had a potential new kidney donor.

Immediately we arranged a meeting with the donor/recipient pair from Cologne and Mrs. Reitmaier.

**Please note**

If you would like to register, please contact: [www.crossover-nierenspenderliste.de](http://www.crossover-nierenspenderliste.de)



**Crossmatch donation**



Drawing: Christopher Will

See also our report on the colloquium in France „Transplantation: a model to be reinvented?“, which also discusses the promotion of crossover donation: [www.bit.ly/DIATRAprof France](http://www.bit.ly/DIATRAprof France)

**Elisabeth, Franz, Lothar and Maria**

With Susanne Reitmaier we, Elisabeth, Franz, Lothar and Maria agreed on a personal meeting for the end of August 2020 in Wolfsburg, where we then got to know each other better. From there we were prompted to contact Dr. Lutz Liefeldt from the Charité transplant office in Berlin. He invited us to perform a crossmatch and hold a first informational talk already at the end of September. The good match was confirmed at this appointment by an additional HLA and epitope matching with a negative cross test and resulted in the invitation to transplantation preparatory examinations in December at the Charité in Berlin, which fortunately turned out well for all four of us. At that time, there was already talk of a surgery date at the beginning of 2021, which, however, did not come about for two reasons: We all could not estimate the effects of the Covid 19 pandemic and its development, and still pending was an appointment with the Living Donation Commission of the Berlin and Brandenburg State Medical Association.

After a further test of patience, we were then invited by the responsible commission to the final appointment at the end of February, at which, in addition to the voluntary nature and the absence of economic interests on the part of the donors, the bond between kidney donor and kidney recipient was to be determined.

Our excitement increased as each pair was invited, by writing, to an interview for half an hour.

However, in the end each of us was individually called before the three-member commission, and during a 40-minute „interrogation“ each member of our group was asked all sorts of impossible questions about the previous personal relationships of our two donor-recipient pairs, and especially about the new recipients.

We left the Medical Association of Berlin and Brandenburg with an uneasy feeling. A week later we received a rejection of our request since, according to the ethics committee, we did not fulfill the requirements of the Transplantation Act of 1997.

The final sentence of the commission's vote gave us hope by mentioning the chance for a second appointment after one year.

Our supervising medical team under the lead of Professor Dr. Klemens Budde from the Charité was just as disappointed as we were.

We gathered all the information and resources to meet the requirements of Section 8 of the Transplantation Act (TPG). We developed a positive energy and after further meetings we contacted the commission to get our follow-up appointment.

We were again supported by Dr. Liefeldt and Professor Budde through additional discussions and video conferences.

Equally important was the symposium of the Federal Ministry of Health at the end of June 2021, which was attended by Mrs. Reitmaier as chairperson of the association „Crossover Kidney Donor List“ [Editor's note: The report can be downloaded at <https://bit.ly/BMG-Bericht>] and where Prof. Budde used our example to explain that the promotion of crossover organ donation could help our kidney recipients in a direct way while also relieving the organ donation waiting list.

Thanks to all our efforts we were invited again to the Living Donation Commission already at the beginning of July. This time the four of us were called in at the same time and after only 15 minutes the commission dismissed us with a positive vote.

The Charité physician in charge of our quartet, Dr. Liefeldt, then informed us of a transplant date for October 2021. The transplantation was successful, our blood values improved in a short time. We noticed this in our physical well-being, and the donors could be discharged from the Charité after only a few days. The recipients remained at the Charité for a few more days for observation, as their blood values were checked daily in order to adjust their medication.

We would like to thank all those involved, in particular Susanne Reitmaier, Dr. Agnes Cseh, Dr. Lutz Liefeldt and Professor Dr. Klemens Budde as well as our surgeons Professor Dr. Frank Friedersdorff, Professor Dr. Robert Öllinger, Dr. Brigitta Globke and Dr. Robert Peters for their commitment to us and to Crossover Living Kidney Donation. We wish them continued success in facilitating this form of donation.

We hope that our children and grandchildren, who have inherited our genetics, will find such dedicated helpers and, with an improved transplant law, will have a better chance of survival.

## The Crossover Donation: An overview

Questions for Professor Dr. Klemens Budde, Head of Transplantation, Specialist for Internal Medicine and Nephrology, Hypertensiologist DHL, Charité

### **Many affected people travel abroad for a crossover donation. Why don't they do it in Germany? Is it illegal here?**

Unfortunately, it is true that some patients have traveled abroad for crossover transplantation because the legal situation in Germany is somewhat more complex than in other countries. However, crossover transplantation is certainly not illegal in Germany and has already been successfully performed by several centers in Germany. At Charité, we have already transplanted two couples through crossover transplants in 2007 and we will celebrate the 15th anniversary together in January, as both kidneys continue to function well and the donors are also doing well.

To protect against organ trafficking, the Transplantation Act (TPG) stipulated 25 years ago that organ removal for the purpose of transplantation is only permissible for transplantation to relatives, spouses or other persons „who are obviously close to the donor in a special personal relationship.“ Living donor commissions at medical associations verify the voluntariness of the donor, adequate risk disclosure, and possible financial aspects to rule out organ trafficking. Although it is not clear who should verify close personal ties, this is also done by the living donation commissions in the absence of alternatives.

In the case of crossover transplantation, there is a special feature that legislators did not have in mind 25 years ago. Although in the case of crossover donation each couple has a special bond with each other, and the purpose of organ removal is to provide one's own partner with a transplanted kidney, de facto the organ donor is not one's own partner, but the organ donor from the other couple. Thus, at least initially, there is

no „obvious close personal affinity“ and the existence of a common „community of fate“ or mutual sympathy is not considered sufficient by some lawyers. Thus, in order for crossover transplantation to be legally sound, more than just a „getting to know each other“ must take place in the run-up to the transplantation, but rather „a personal bond that is invested beyond the donation“ must develop. In summary, crossover transplantation is legal in Germany, but very difficult to implement in practice.

When describing this, the absurdity of the current legal situation becomes clear, whereby the question of the examination of the „obvious close personal relationship“ is not at all regulated in a legally flawless manner, and the clarification of personal relationships is rightly regarded by those affected as inquisitorial and as an unreasonable interference in personal matters.

Fortunately, there was a symposium of the Ministry of Health in June, which determined the need to change the law. A few weeks ago in Berlin, the German Medical Congress also called on legislators to make changes in order to enable crossover transplantation in Germany with a better legal situation.

### **Who – other than family members – may donate? Can a friend donate? How and by which institution is it assessed how close the relationship is between donor and recipient?**

As stated above, in Germany anyone „who is obviously close to the recipient in a special personal relationship“ may donate. In addition to the aforementioned Living Donation Commission - and usually before its meeting - the presentation at the transplant center and the evaluation there, which includes a detailed psychological network test, includes

questions about the relationship between donor and recipient and the significance of the donation for the future of this relationship.

### **Is there – besides the kidney – also the possibility of crossover donation for other organs?**

Theoretically, this could also be used for living liver donation, but to my knowledge it has not been practiced so far.

### **If everyone waiting for an organ received a crossover donation, would they all soon receive a suitable organ?**

Crossover donation certainly cannot solve the dramatic organ shortage in Germany. Even in countries where functioning crossover and exchange programs are currently running, it is only a small contribution to improving the situation for some of those affected. However, every kidney that can be transplanted in this way changes the lives of patients on the waiting list and their relatives.

So far, more than 1200 kidneys have been transplanted via such exchange programs in Europe alone, and it is sad that with the catastrophic situation in Germany, we can only use this option to a very limited extent. Only patients who have a potential living kidney donor and for whom compatibility reasons speak against direct donation are eligible for participation in crossover programs. This is estimated to be five to ten percent (even more if blood group incompatibility is included) of all potential living kidney donations. Enabling such living kidney donations in the crossover procedure should thus make a relevant contribution to relieving the waiting list and thus to shortening the waiting times for cadaver kidney donations. The Netherlands is a good example of this.