The Unfortunate Inequalities in Solid Organ Transplantations for Patients in Different EU Countries
My Story

By Borislava Ananieva

Disclaimer: This story is a personal testimony and does ***not represent every patient's experience or views***

How did my story start?

I was born in 1994 in Sofia, Bulgaria. Right from the start, my mother had a feeling something was off and asked for a prophylactic examination. Doctors reassured her that I was a healthy looking and "normal" baby. Fast forward to a year and a half later when I got a severe reaction from a vaccine. Because of this, they found out that I was actually born with only one kidney functioning, and at a very minimal capacity. My parents were hit by the reality that eventually I would need a kidney transplantation, which was impossible in Bulgaria, as solid organ transplants were not done with children at the time.

A hospitalised childhood

I spent my entire childhood in and out of the hospital. At age 5 I was equipped with a definitive nephrostoma, which I had on me for more than 3 years, desperately trying to avoid starting dialysis. The catheter needed to be changed (without anaesthesia, going straight into my kidney) once every few months. Needless to say, these events were incredibly traumatising for me as a child.

They did not want to accept me in any kindergarten because of my stoma bag. Even later on when I started preschool, there were many negative comments trying to stop me from attending a "normal" school. I still remained quite social and never ashamed of my stoma bag filled with urine and tied to my leg. I believe this was only possible because of the amazing support I received from my lovely family and friends.

Pakistan and the beginning of a new life

At age 9 it was time for me to either start dialysis or get a kidney transplantation. As Bulgaria had no experience with solid organ transplantations in children, we were forced to find another way. After research, communication with the hospital and collecting the necessary resources, my family headed to Pakistan, where I had my first kidney transplantation from a living unrelated donor. Please, keep in mind this was in 2003 and some laws were still not in place in the country.

The kidney transplant was a success and on the second day of recovery I told my mother that I felt so energetic; I wanted to play jump-rope in the hallways. I quickly started learning of all the new things I had to change in my life: the strict medication, protecting my belly and the kidney inside, often going to the hospital for tests, and everything else that a transplant patient goes through on a daily basis.

In the following years, I had to slowly learn of all the challenges that transplanted patients face. I was advised not to go back to school in the winter, as my immune system was compromised. I stayed home and my kind teachers were coming over to help me learn the most important parts of the lessons so I would be able to pass the exams.

Finally stability

The next 11 years of my life were what I would call “stable”. I went for a blood and urine test every few months and had the occasional cold or flu but, apart from that, I was feeling healthy and alive. These were, without a doubt, the most care-free years of my life and I am forever grateful that I had the opportunity to experience them in that way. I was so happy to be able to live like a “healthy” person - go on vacations, live a care-free daily life and enjoy my adolescent years - without worrying that at any moment my condition could catch me off guard.

I think my home country was a great place to spend these years in, however we can never know or plan when our health will worsen. Unfortunately, Bulgaria was not a good place for me to be in once my health became unstable.

Unstable and going downhill

In 2014 my Creatinine began to rise. I started having high Urea levels, suffered from Proteinuria, and in general started feeling bad, nauseous and could not sleep. The feedback I received from Bulgarian doctors was that my kidney had run its course and I should just wait to go on dialysis. This way I could be put on the waiting list for a kidney transplantation. Bulgaria is one of the lowest in the world[1] [2] when it comes to the amount of organ donors and transplantations made. With so many people on the waiting list and so few transplantations happening in the country, this did not seem like an option. Having seen how people recover and live with their transplantations in Bulgaria, while also unfortunately having lost a few friends, I decided it was time to look abroad for better options.

I was lucky enough to have a few healthy family members that offered to donate their kidney to me. This meant that I had to search for the best possible option for both me and my donor. My amazing grandmother, aged 66 at the time, was a great match and agreed selflessly to donate her kidney to me. My decision to search abroad was brought on by the fact that Bulgaria still does not use the laparoscopic method for kidney extraction from the donor. Instead, they still use the old method, which can be much harder to recover from for the donor.

With my grandmother as the donor, and with the support of my incredible mother, we settled on Turkey as the best option for my second kidney transplantation. The hospital invited us for an evaluation and after seeing my condition and the biopsy result, they suggested a few treatments to extend my time with the kidney I had for as long as possible before having the next transplant. I had a change of immunosuppressants, additional medications included in my therapy, 4 courses of plasmapheresis, ATG treatment. This resulted in an additional 4 years with my Pakistani kidney! It was not easy, but I was so thankful that I did not need to go on dialysis!

---

[1] The page should be translated to English in the browser (right click and translate), as the English version of the website does not show the data for previous years

[2] Available at:
https://iamn.bg/%d1%82%d1%80%d0%b0%d0%bd%d1%81%d0%bf%d0%bb%d0%b0%d0%bd%d1%82%d0%b0%d1%86%d0%b8%d0%b8/%d1%81%d1%82%d0%b0%d1%82%d0%b8%d1%81%d1%82%d0%b8%d0%ba%d0%b0-%d0%be%d1%80%d0%b3%d0%b0%d0%bd%d0%bd%d0%b8-%d1%82%d1%80%d0%b0%d0%bd%d1%81%d0%bf%d0%bb%d0%b0%d0%bd%d1%82%d0%b0%d1%86%d0%b8%d0%b8/

24 years old and a two-time kidney transplant patient

In the beginning of 2018, my condition was getting worse and worse, and it was obvious that the time had come for my second kidney transplantation. We headed to Turkey, where on 27 February my second kidney transplantation was a success thanks to the outstanding specialists in Gaziosmanpaşa Hospital in Istanbul! Going out of the ICU, I saw my grandmother already walking slowly in the hallway of the hospital. Within a week, we were both stable and discharged from the hospital.

I can never express in words how grateful I am to have had the opportunity to receive such holistic care before, during and after transplantation.

Post transplant care in Bulgaria

Coming back to my home country I was immediately faced with the reality that, until my documents for the immunosuppressants were filed and approved, I needed to somehow find them myself. I had to take high doses of the immunosuppressants in the beginning, but it took a full month until I could receive my medication for free. This meant that I had to buy them myself for a while, and they were in no way cheap. After this issue was resolved and I had finally started to receive the medication for free, I was faced with yet another issue which could influence my health and everything I had fought for until that moment.

In Bulgaria, there are only 2 centres where transplanted patients can go for a follow-up. In addition, each transplant patient has a limit on the blood and urine analyses they are allowed each year. Of course, this does not take into consideration your current health status or any health issues you might be facing. In my case, my Everolimus level would not settle at the appropriate level, something fairly common in newly transplanted patients. This meant, I had to increase my dose, wait a week, have a blood test to see the results, change the dose again, wait another week, and so on and so on. After a few months of back and forth my levels settled and I only had to go for blood and urine analyses. Unfortunately, later on I had more complications and had to be tested tests more frequently. I was very surprised to find out that I had reached the limit of free tests, and had to now pay out of pocket for any additional blood or urine analysis I needed. It is worth keeping in mind that I was still recovering from my transplantation and could not really go back to work full time, while my disability benefits at the time were 71 EUR per month. This only showed me how doomed I would be if I health issues continued while I stayed in Bulgaria. Because of this, I started looking for countries to move to where I could find better healthcare for transplant patients.

Becoming a health immigrant in Belgium

In April of 2019 I moved to Brussels, Belgium, where I started a new job. Something that made a good impression immediately, was that there was already a number of transplantation centres in Brussels alone. It was so good to see that I finally had options. I was quickly included in the list of transplanted patients in Belgium. This meant I could immediately get my immunosuppressants with just a prescription from the nephrologist, I could easily schedule my appointments for blood and urine tests, could have quick and easy communication with the nephrologists, and the few times I needed urgent care there was immediate action. All of these things are absolutely crucial to any transplant patient.

Since I moved to Belgium, there have been more than a few instances where I had a hard time keeping my condition stable. I am incredibly thankful and lucky to have received such flexible, kind and structured care. Having seen how transplant patients are treated and cared for in my home country, I unfortunately do not plan to go back to there. When a person is going through such a complicated and hard time, and is physically and mentally exhausted, it is extremely important to feel safe, taken care of, and to be able to trust that the healthcare system, healthcare providers and the government have your best interest at heart

My personal view

As a person that is currently 28 years old, who had to go through everything that was mentioned above, I can only be happy to have survived despite all the challenges.

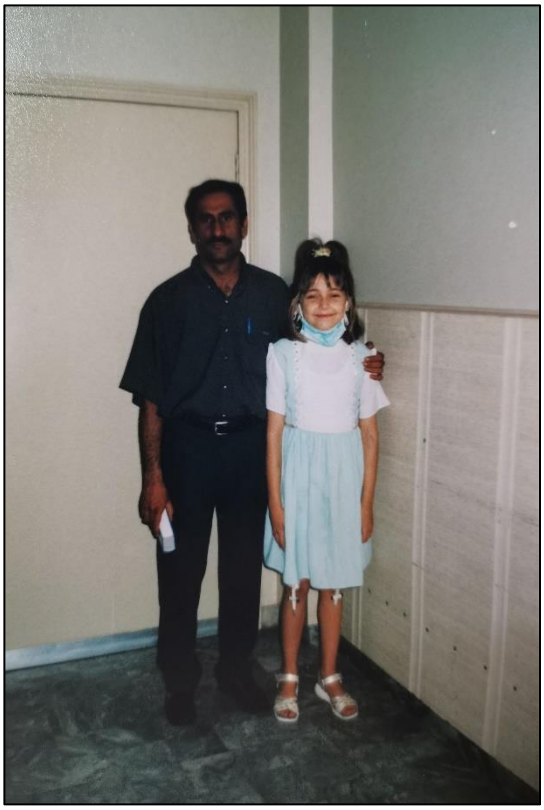
I believe it is always important to map all your options and check for other opinions from different specialists. If you are not happy with the care you are receiving and you feel that it has a bad influence on your quality of life, it is your right to search for better care elsewhere. I also realise how lucky I am to be a in a country that is a member of the European Union, meaning I can take advantage of all the benefits that come with that fact.

I want to emphasise that this is <u>my own personal experience</u>. Of course, it is not the same for everybody. As much as I love my home country, it was only a suitable place to live in while my health was stable. Unfortunately, having stable health can never be guaranteed nor planned.

Pictures:

Me as a child with a stoma bag

First transplantation in Pakistan



First transplantation in Pakistan

With my teacher after the first transplant

With my mother and grandmother after the second transplantation