

My story for the World Transplant Game about my transplant on 9 August 2019.

Madam, sir,

Thank you for your email.

Allow me to share with you my life story that can be shared on the World Transplant Games network.

My name is Fabiano, I was born 38 years ago in Morges, in the canton of Vaud in Switzerland. I am married and have twin daughters who are almost six years old.

I have been working since the age of 16 as a Plasterer-Painter in the family business, but had in 2015 because it was no longer compatible with my illness.

I lived a 'normal' life until 2015 but in that year, after many tests, I was diagnosed with three overlapping rare autoimmune diseases. To this it is still uncertain to give a precise name to a disease.

Since then my life has changed somewhat.

I have been working since the age of 16 as a Plasterer-Painter in the family business, but unfortunately I had to change path in 2015 because it was no longer compatible with my illness.

Therefore, in early 2016, I started a professional reconversion as a Socio-Professional teacher accompanying people with disabilities in sheltered workshops and for which I was training in a graduate school in order to obtain my diploma, but health decided otherwise ...

In 2018, I underwent a six-session chemotherapy treatment from July to December.

At the end of 2018 and early 2019 my health deteriorated rapidly and I had to be on oxygen from time to time at the beginning, but in the last few months I was on oxygen 24 hours a day and only rarely went out with my oxygen bag in order to breathe better.

Even when I was showering I was connected by oxygen, as I liked to call my oxygen pipe "my leash", but without it I could hardly breathe.

Seeing the situation getting worse, the doctors suggested that I should have a pre-transplant check-up in order to be put on the organ waiting list.

In June 2019 I signed the consent to be on the waiting list for Swiss Transplant which was a very special and emotional step.

Nevertheless, since the beginning of 2019, I have been hospitalised on numerous occasions, one of which was for more than a month.

In spite of that, during this whole period I continued to work, to go to classes and take my first and second year exams. And above all to fight and stay positive in order to keep going as far as possible.

Despite my positive attitude and strength, the disease was stronger and my health got at its worst by deteriorating very rapidly, at this moment I only had 20% of respiratory capacity left.

Here is an anecdote during that time that will remain ingrained in me for a long time:

I had to go to my last exam in order to validate my second year of study so I went in pretending nothing happened. Nobody knew I was sick and on oxygen.

Before going up to the audition room, I took my last breath of oxygen in my car and went to the exam as if nothing had happened.

I went in front of the jury by passing this test in the best possible way and immediately got back in my car in order to breathe with my oxygen again and catch my breath.

Since that day, I have had to stop this professional reconversion, because the invalidity insurance office no longer wants to accompany me due to a medical situation too severe.

In spite of this I always kept hope and a mental strength at a maximum level in order to move forward.

A few days after this, I got hospitalized for more than three weeks and at this point I was taken off the transplant waiting list because my health was too weak and no longer compatible with a lung transplant. It was also one of the significant moments, because it was as if everything was starting all over again and above all the solution to a recovery was being taken away from me.

I left the hospital after this long hospitalisation trying to get back on my feet as soon as possible so that I could be put back on the waiting list.

I called the transplant coordinator who has been following me since the beginning of the process and asked if they could put me back on the list, as I was feeling better, even though I was stuck at home with oxygen 24 hours a day with immense fatigue but I insisted on getting back on the list.

The coordinator called me back two days later and told me that after discussion with the doctors they are putting me back on the waiting list.

That was mid-July 2019 and it was a great moment of relief.

At that moment I was feeling that I was at the end of this intense race against life.

I was totally exhausted on a physical level, but above all, and what had always been my strength up to that moment and what kept me going up to that point was my psychic and moral strength collapsing, I couldn't take it anymore and I was at the end...

August 8 and 9, 2019, dates I will never forget.

On August 8th at the end of the day my phone rings and it was the transplant coordinator from the CHUV who is on the other end of the line telling me that there might be lungs for me, you have to come....

But what an incredible and unique feeling I had at that moment, I went through all the emotions that a human being can go through.

A unique moment where everything goes from joy to sadness in the space of a few seconds.

We were at that moment starting to prepare the dinner with my wife and our four and a half year old twin daughters were playing in their room.

After that phone call and while waiting for the ambulance transport which was due within the hour, we had time to talk with my wife and children.

It was a very strong and moving moment, we had time to talk if it wasn't going to go well, but also the chance to be able to do this transplant. We also took a moment to explain to the girls that daddy would be away for a while and that he would be leaving for the hospital in a few minutes

My phone rings again and it's the ambulance that's downstairs, we all go down together, I give a last kiss to my wife and daughters and I get into the ambulance.

What will stay with me in my memory is the moment when the ambulance starts and I say goodbye to my family, at that moment everything jostles in my head.

This may be the last time I see them, will my daughters understand what's going on, if it doesn't go well, have I left everything as best I can, etc. I don't know.

During the 20 minute drive from the hospital house I really became aware at that moment of what was going to happen in the next few hours.

I arrived at the CHUV with the SwissTransplant ambulance via the emergency room, made me wait a while as they were not aware of my arrival and we took it as a joke with the hospital staff and it relaxed this very special moment.

After about 30 minutes the transplant coordinator comes to pick me up and explains the process a little bit and takes me to the room. A nurse gives me the various routine checks and prepares me for the operation. I see the various doctors, anaesthetists and surgeons coming by for the latest explanations and information about the transplant.

Around 10pm they told me that the operation is scheduled for 3am and that they would come and get me at around 2:15am to take me down to the block and in the meantime I could sleep.

There is also a parameter that I haven't talked about, but that really needs to be taken into account throughout the whole process is that from the moment you receive the phone until the moment you go into the operating room

there is always the risk that everything will be cancelled and the graft is not compatible.

In spite of all this I still managed to get some rest, but of course I couldn't sleep, I was serene in spite of everything and confident.

Around 2:15 am on August 9, 2019, they came to get me to go down to the operating room.

The time to go there to get ready and to arrive at the preoperative room it is about 03:00 in the morning and there I go into the operating room for about 12 hours of surgery.

After a few days in an artificial coma, I woke up in the intensive care unit with the greatest gift anyone can receive in a lifetime - the gift of two lungs (thanks to my donor).

I stay a little less than a month at the CHUV after a week of intensive care, a week in continuous care and a week and a half in my "partitioned" room in order to avoid any risk of contamination.

I gently start the rehabilitation with the physiotherapists and I do my best to get out of the hospital as soon as possible. Luckily I have a training bike right in front of my room and I ride it daily to recover as quickly as possible.

I come out of the hospital stronger than ever, but of course I am transplanted with both lungs and life will never be the same as before and every day and one day is a life gained.
During my re-education which was rather fast, because being super motivated, it is something that is very much like me in everything I do.

A few months of rehabilitation and adaptation to my new life and the question of taking up sport again came up.

But what kind of sport should you do when you are transplanted?

After several months of questioning on this subject, one thing seemed more than logical to me.
My wife working in a golf shop and where there is a golf simulator on site I thought, why not GOLF since you would like to play it.

After some tries which are more than reasonable, my wife and I go to Villars-sur-Ollon for a weekend to play GOLF together with our daughters and that's when it all clicked...

This is the sport I want to practice for my second life.

And as I am a person who likes challenges, I find out that there is competition for transplant patients and after much research I find on the SwissTransplant website that they talk about the WORLD TRANSPLANT GAME.

After reading the explanations, I say to myself what better than such a powerful challenge in order to move forward as well as possible.

My decision and decision I absolutely want to participate in the WORLD TRANSPLANT GAME as a golfer.

To date, and after starting golf only three and a half months ago, I have passed all the exams and obtained my golf course permit at the end of October 2020.

I am now officially a Golfer!

At the moment I play golf regularly and as often as possible and according to my health, but on average between two and three times a week I play a 9 or 18 hole course and of course I do so in order to get better and better from the driving range for at least two hours at least.

The aim is to reach the best possible level for this WORLD TRANSPLANT GAME challenge and why not win them one day.

I am really looking forward to participating and being able to share with other transplant patients who live in the same conditions as me.

I recently set up an Instagram account (<http://www.instagram.com/fab.09.08.19>) which is dedicated to my new life and this wonderful challenge. Where I share a little bit my new life as a transplant patient and the challenge of participating in the WTC and this account also allows me to exchange with other transplant patients.

Here is the link (<https://www.leetchi.com/c/fabwtg>)of my participative jackpot in order to reach my goal of the World Transplant Game that I just made. Also this Thursday November 19th a video presentation of the WTG with me will be put online on Instagram via a golf influencer. I can transmit it to you if needed.

Here are the main lines, but a book would be needed to explain the whole process from the announcement of the diseases before and after the transplant my daily struggle, the resilience, the strength, the sadness, the joy?

I would also like to emphasise the fact that since this transplant we have been living together in my body and that it is thanks to my donor that I am still here today and that I can start my second life in the best possible way.

In a way, being active, having a goal and doing as much as possible is a way of thanking him every day.

I also have a thought for his family, who after the loss of a loved one, allow me to live a new life.

You can contact me without any other and I remain at your disposal if you have any questions or additional information concerning this project.



Fabiano Paratore