

## **The place of birth makes the difference – a patient's view**

This is my family celebrating Mother's Day in May 2005. French daddy, Hungarian mom, 7-year-old little girl. We lived happily in France  
A "perfect European model family".

We decided to have a second child.

X-mas 2005, I got the most beautiful present: the ultrasound result, which revealed that I was pregnant with a little boy. It was a happy and relaxed pregnancy. I was the dream for every gynaecologist: A 31-year-old mother, who did not smoke nor drink, with a previous healthy pregnancy and natural, uncomplicated birth.

In the 25<sup>th</sup> week of my pregnancy, my gynaecologist authorized one last flight: he let me go for a 2 weeks vacation to take my daughter to visit my family in Hungary.

2 days before our return to France I got sick.

First, I had a headache, then my legs and arms got heavy and swollen, all of a sudden I was feeling extremely tired and I dragged myself into the closest hospital.

I had pre-eclampsia.

Till that moment, I had no idea about pre-eclampsia at all.

I have only vague memories of that time and what happened during the next weeks.

But I remember well the emergency doctor who explained to my frightened husband, who was then 1300 km away from us, on the phone, what was happening to his wife and his unborn son, and that they would have to deliver the baby immediately.

My son was born in the 27<sup>th</sup> week of pregnancy with 890 gr.

I remember the moment when my son was born, and I saw his tiny feet and a neonatologist running away with him as he had no signs of life.

I will never forget the moment when I woke up in intensive care and the pain I felt when I realized that this was not a bad dream, this was the reality.

My tummy was empty, no baby inside.

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My husband rushed to us from France. I will always remember the first time we met our son around 24 hours after his birth. I tried to prepare myself for the sight of my son, but you cannot prepare for this.

Five days after his birth, the hospital released me and I had to leave my baby there. Alone. I was devastated.

At the same time, my husband had to go back to France for work, and took with him our then 8-years-old daughter-the day of her birthday!

The NICU door will haunt me for the rest of my life. I was afraid of what was waiting for me behind that door. For the next 14 weeks, I stood in front of that door twice a day and pressed the bell.

Would they open quickly or would I need to wait? If I had to wait, was it because something was going wrong on the other side of the door? Was it my son?

I insisted on calling the NICU every morning at the same time. Every day I wrote down every little detail on his baby journal, and also added one photo for every day. If anything happened, I needed memories. I needed to prove his existence.

Often, I found myself NOT looking at my baby BUT at the monitors.

I tried to think that this is not my son, to avoid getting too attached to him. I did not want to feel any pain if he would not make it and he died. Although everybody tried to convince me that I had to be happy as I survived, I blamed myself for his preterm birth.

I felt invisible in the hospital. Doctors, nurses were overworked and did not have time for a mother who was depressed. I had no psychological help. There were 6-7 incubators for 1 nurse and 1-2 neonatologist in every shift.

At that time, I was confident and felt that my baby was in good hands. Never, not for one minute I questioned that my son and I did not receive the best treatment and care. Now, in hindsight, I know how dangerous this situation was.

Every day when I walked into the NICU, I only watched incubator number 23.

The doctors came by, often said some cliché like my favourite "two steps forward, one step back" and then they left me alone. The visiting time for each child was 20 minutes, two times a day.

I remember the exact day and the exact hour, when my son started to breathe without any machine. At that moment he was born a second time, but I was not there. They told me via phone.

The moment when I could hold him in my arms for the first time is equally unforgettable. He was then 12 weeks old.

Then one morning, they told me I can take my son home, and all of a sudden he was lying there next to me in the bed, a little 2-kg baby, who was on monitors only few hours before. I felt completely incompetent and did not dare to sleep for weeks in a row. I had to watch my son during the night, always checking: Is he still breathing?

After my son got out of the NICU, I felt many things, but I missed the most important feeling: I did not feel like his mother.

I felt more like a nurse and did not let anyone near him; When I fed him, I was wearing the green NICU uniform and a mask for weeks.

It took another 2.5 months until we both could take a flight to go home, back to France. You cannot imagine the financial burden: for nearly six months, we paid 2 household charges, taxi fees, phone, internet and flight tickets which had absorbed all our reserves.

And if you think the rollercoaster got easier, well we learnt that the French and Swiss social system is extremely weak and without enough information and a good adviser you can slip out really easy from it. During follow-up nobody took my worries, my comments seriously. My son's development was extremely slow. After 2,5 years of pleading for an MRI, they finally gave us a diagnosis. My son has PVL, profound brain damage. Equal mentally and physically disabled child.

Our son became a fantastic little boy. He is a 5-6 years old little child who lives in the body of a 13 years old boy. He walks, he is happy, he speaks 2 languages, he has his own friends.

But he cannot change his clothes, he is not able to write or read, he will never be an independent adult, he will always need someone around him 24-7.

For about 13 years now as a mentor preemie mom, I heard many stories from families like mine – throughout EUROPE. We are not a special, unique case. During these years I learned a lot about the neonatal practices of domestic and international levels. Finally, I dare say out loud: my son did not get the best practice in Hungary, and France and Switzerland failed during follow-up. Was he the unfortunate little boy who was born in a wrong country, in a wrong city or in a wrong NICU?

No one knows whether my son would be healthy if he was born in France or Switzerland. But 20 minutes visiting time twice a day has definitely not helped to let him thrive. He couldn't benefit from skin-to-skin care, he wasn't breastfed. These may seem "simple things" but we know for a long time, that these are the things that contribute to making a difference.

Our family has in the meanwhile accepted this destiny and we are able to cope with it - some days more, some days less. But I have never given up, I fought for my son and for my family.

Because of these differences in care between countries, but even between single hospitals, I work voluntarily in the Hungarian parent organisation. I want to ensure that other pregnant women, other families don't have to live through the hell I, we went. 13 years later, the very same NICU does the very same, harmful practice. 20 minutes visiting time twice a day. Couple of kilometres away, in the same city, 2 other NIC-s let parents be with their premature children 24/7. Why? How is this possible? How can we let such differences happen? How can we provide the best possible care for such vulnerable little children, if there are no widely accepted regulations?

We need harmonised standards of care for our premature babies throughout Europe as all European preterm babies have a right to the same care, survival chances and to a healthy life. Please help us to make it happen!

Thank you for your attention!