

# Becoming an advocate for newborn care in Hungary

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Undertaking an observation during FINE 2

**W**hen did my 'patient expert' journey begin? Probably during my nursing education in the early 1990s, I was fortunate enough to try myself out in intensive care with all of the beauties and challenges within. But 10 years later I became a 'naive patient'. I never thought there could be such a deep, gut-wrenching, paralyzing pain in every part of my body. I thought, this can't happen to me, I can't give birth early, way too early. Many women have thought that and sadly, many will continue to think that until the unthinkable happens.

I remember standing in the hallway of the deserted maternity clinic in the evening. The smell of chemicals, a distant baby crying, snippets of conversations, a typical obstetric setting. In my hand I clutched the day's breastmilk. As I stood outside the neonatal intensive care unit (NICU) door I tried to recall how I got there.

I was a Hungarian mom and lived happily in the French-Swiss border, close to Geneva with my French husband and 7-year-old little girl. I was pregnant with our second child. A 31-year-old mother, who did not smoke, nor drink, with a previous healthy pregnancy and a natural, uncomplicated pregnancy and birth.

During the 25th week of my pregnancy, my gynaecologist authorized one last flight: he let me go for a two week vacation to take my daughter to visit our family in Hungary. Two days

before our return to France I became unwell. 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.

## Memories that triggered action

I remember 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. They would have to deliver the baby immediately. My son was born in the 27th week of pregnancy and weighed 890 grams at birth. I remember the moment when my son was born. I saw his tiny feet as a neonatologist was running away with him as he had no signs of life. 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.

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?

The doctors came by and often said some cliché like 'two steps forward, one step back' and then they left me alone. The visiting time for each infant was 20 minutes, twice a day. I insisted on calling the NICU every morning at the same time, I had my daily rituals. Every day I wrote down every little detail in his baby journal, and also added one photo for every day. If anything happened, I knew 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 had survived, I blamed myself for his preterm birth. I was a mother of two children, but what was the reality? One of them was 1300km away from me and the other one was locked down in a NICU, where I had to ask permission to see him. I couldn't be a mother to any of my children, it was torture. I felt invisible in the hospital. The doctors and nurses were overworked and did not have time to support a mother who was depressed. I had no psychological help. Each nurse cared for between six and seven infants in incubators, and there were one-two neonatologists each shift.



After discharge

At that time, I was confident and felt that my baby was in good hands. Never, not for one minute did I question that my son and I did not receive the best treatment and care. Now, in hindsight, I know how dangerous this situation was. 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 on the phone. The moment when I could hold

him in my arms for the first time is equally unforgettable. He was then 12 weeks old.

### There must be a better way

Eighteen years ago he went through traditional, and unfortunately outdated, non evidence-based neonatal care. I had two visits for 20 minutes each a day to be with my baby, who was I was told was 'ready' to be visited. I could only look at him, I had to ask permission even to touch him or take a picture of him. The main reason was: as they say: to avoid infection. I imagined I had a biological bomb, planted in my head from the first moment I set foot at the NICU and it went on for 14 weeks. I was afraid to kiss my own child for a year. I did not let anyone to touch him beside his father and sister for a year! They were giving formula milk to my baby as my breastmilk dried up very quickly because of my stress, and misleading information. He received good old cluster care where his sleep cycles, pain and stress were ignored, he was positioned on his back without any support for his shoulders, legs or knees while he was in the incubator.

Then one morning, the staff told me I could take my son home. All of a sudden, he was lying there next to me in the bed, a little two-kilogram baby, who was on monitors only few hours before. I felt completely incompetent and did not dare to sleep for weeks. I was his monitor during the night: Is he still breathing? How on earth could the NICU staff think I could possibly take care of this baby? Is it really my baby because I still don't feel it. And I knew about attachment and bonding as

I already have an eight year old daughter. 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. We didn't receive any diagnosis, only 'this child got away with it'. No diagnosis means no prognosis it means go home and have a happy life.

It took another two and a half months before we both could take a flight to go home, back to France. We learned that the French and Swiss social system are extremely weak and do not have enough information or a good adviser so it is easy to slip out of the social system. During follow-up nobody took my worries, my comments seriously. My son's development was extremely slow. We were followed in three different countries, but there was no consistency.

### Becoming an advocate

It took me two and a half years to learn how to become the voice of my child, to stand up for his rights and stand up for my rights as a mother. They kept repeating, he is an extremely preterm BOY, why am I so impatient?

After two and a half years we finally got a diagnosis. My son has periventricular leukomalacia (PVL) and cerebral palsy (CP), which equals a mentally and physically disabled child. Therapies came in line, some were useless, some dramatically improved my son's development day by day and changed the quality of his and my family's life. Some were recommended by the neurologist, some by the pediatrician. I received ideas from the parent group, from the internet, and Google doctor became my best friend. At the beginning I did not question the scientific evidence of any of the interventions, most of them largely expensive and not paid or reimbursed by health insurance. Results were coming little by little. My son started to walk and talk around the age of five, he became relatively independent and managed his daily routines. Feeding was always an issue, and still is. If he finished his food, I doubled the portion. The first 10 years of his life this was my 'mothermeter'. He started school in a special class and continued his studies in a special school adapted to his handicap. So, I had to give up my job, I became a full time social assistant to navigate between medical appointments, therapies, interventions, school, finance and insurance.

What does it take to become a dedicated advocate and create the Right(s) beside you Association for premature babies in Hungary? It took a traumatic birth and NICU experience with an extreme premature baby who weighed barely 600 grams in the first week and who, has to live with the consequences of his early arrival for the rest of his life.

It took a minimum of one neonatologist (special admiration to Dr. Csaba Nádor) who believed that with good patient-centered and family integrated care you can protect the brain and neurodevelopment of these babies. There needs at least one NICU nurse who believes that by involving parents, even better care can be provided and the baby will leave for home with



18 years later

competent parents. Our association was founded in September 2015 with the aim of bringing together in a unique way doctors, health professionals, decision makers and NGOs representing parents of premature babies to ensure that every baby born prematurely or sick has the best possible chance of survival with the best possible quality of life. To give everything I didn't have 18 years ago, up-to-date, evidence-based information about premature birth-related diseases, professional help and social support.

### Call to action

As developmental care was NOT part of the nursing curriculum, the association strongly advocated to establish the FINE

(Family and Infant Neurodevelopmental Education) training as a basic education in every level III NICU in Hungary. With the help of volunteer neonatologists, 'veteran parents' whose child was born extremely preterm, we fully translated the educational materials and organised the trainings. These parents have been helping the international trainers, initially as translators, and now themselves involved in training part of the faculty. Along the way we learned how to get finance for the training and we started to collaborate with industry partners. We have learned how to climb back through the window of the decision-makers when we are thrown out the door. There was a need for an evidence-based handbook specially for NICU nurses. We translated the Neonatal Nursing Care Handbook by Carol Kenner and Judy Wright Lott. We started to advocate for the NICU nurses as we faced huge challenges, how to implement neurodevelopmental care on a daily basis. Closed-system workplaces are typically teams that deal with life-and-death situations. Their work, and the success of their work, depends on everyone knowing exactly what to do, and in what order - they are maximally interdependent. We had to be aware of their mental health state and the workload they faced day by day.

During these 18 years I have heard lots of stories from families like mine – throughout EUROPE and around the world. We are not a special unique case. During these years I learned a lot about the neonatal practices at both domestic and international levels. Finally, I dare to say out loud: my son did not get the best practice in Hungary. France and Switzerland failed during follow-up. Was my son the unfortunate little boy who was born in the wrong country, in a wrong city or in a wrong NICU? Was it my fault I couldn't become a COMPETENT mother for my son, to stand up for his right and advocate for him correctly?

Today we know, I know that 'every care is brain care', every touch and word has lifelong consequences and we have to protect the brain of every preterm baby, but I wish I knew back then....



### Mission

The NFI improves the future of all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP care.

*Adopted by the NFI Board, June 29, 2022*

### Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes.

*Adopted by the NFI Board, October 20, 2017*