

Most families are not prepared for the possibility of a premature delivery, and the experience of having a premature or fragile infant can be overwhelming. Providing information regarding prematurity prior to a baby's delivery and during a baby's course in the neonatal intensive care unit and through discharge to home is imperative, yet these resources are not always readily available and in some countries, are very limited if available at all.

In this mother's story, we hear firsthand what it was like for her and her husband when their baby girls were delivered and how the lack of information about prematurity and resources for parents, as well as, their personal loss spurred her to take action and advocate for change.

My Personal Loss Provoked Me To Fight

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It was an amazing summer back in 2008 as we were on vacation with friends. After several Intracytoplasmic Sperm Injection (ICSI) procedures, I was pregnant with twins. We were expecting two little girls. I remember the first kicks and the butterflies in my belly. In week 21 of my pregnancy, my doctor saw a problem. There was a small amount of amniotic liquid, and he told me to go home and get a lot of bed rest. After a while, I started bleeding and went to the hospital. I was in shock with nightmarish fears. Everything had changed within a few hours. My water broke and I feared this was the beginning of the end. My husband spent the night with me trying to comfort me. Later he told me that he was going outside so that he could cry alone. I was not able to see the sadness in his eyes.

I was in much pain and was laboring for 22 hours and then gave birth to two baby girls. I was only 24 weeks pregnant. One of my babies was 730 grams and the other 680 grams. After birth, the babies were taken away immediately, and I was not able to see them. At that time this was the practice in Bulgaria. I went back to my room and fell asleep. I was so excited yet angry. I remember that the first thing I wanted when I woke up was to go home and start a new life. However, none of this has happened.

Feelings of shock and disbelief

I was called into the NICU to see my babies. In the beginning, I was crying and in denial about having my babies. I was sure both had died. And then I saw the most perfect and beautiful babies in the incubator lying next to each other wearing white and pink caps. There were so many cables and wires, and I will always remember the terrible noise in the ward.

After two days, my smallest baby died. She was too fragile and had no chance of survival. She never received a name or a birth certificate. She was considered biological rubbish and was taken away and discarded.

After 7 days, according to Bulgarian law, we gave a name to our only live child – Alexandra. She spent five months in the NICU, and it was a huge fight for her. Alexandra was in a pri-

vate hospital, and I was going to see her every day. At that time, I was not allowed to breast-feed. After I gave birth, the doctor gave me pills to stop my milk. They believed there was no chance for my baby to survive! I was not allowed to do kangaroo care and was only allowed a few minutes next to the incubator. I hugged Alexandra for the first time four months after her birth. It was a birthday present from my husband, but she was still attached to the breathing machine.

It was a long treatment without success and we arranged for Alexandra to be transferred to another hospital in Israel. We paid a huge amount of money to hire an air ambulance because there were none in Bulgaria and there are still none today in 2023. The ambulance came and the doctors realized she was in terrible condition and was intubated and would not transfer her in this condition. We were returned to the hospital after five hours. Alexandra was getting worse day by day and three days after this situation, we were called to say goodbye to her. It was the worst moment in my life. I went to Alexandra's room for the last time and approached the incubator. Her oxygen saturation was between 80 and 40. She was ready to go. My husband stayed until dawn. I was there, talking to her, touching her but her skin was cold. I knew it was over. I said to her – "My dear Alexandra, now you can go. We will love you forever". I waited for the scariest phone call which came at 4 PM. Alexandra was gone. My whole world broke. I



Alexandra



Martin and Joana at 6 months of age



Family photo taken in 2021. Martin and Joana are 11 years old

was terrified and cried for days. Alexandra was buried next to my grandmother. There is nothing worse than to bury a child before yourself.

Next story - Hope

In 2010, I was pregnant again with twins – a boy and a girl. I was happy and at the same time terrified. I spent seven months on bed rest and medication, praying every day for a miracle to happen.

On the 9th of September in 2008, my first set of twins were delivered, and my first baby died on the 11th of September. My second set of twins were born on the 11th of September 2010 at 29 weeks gestation. They were tiny little miracles. Joana weighed 930 grams and Martin 1170 grams. This time I was able to breastfeed, hug, and touch them every day. They spent three months in the hospital and came home healthy and were amazing little beings.

The experience of having a baby born prematurely is difficult, sad, challenging, and amazing all at the same time. To be a parent of a premature baby is a thorny path that we must walk. I am more than happy and thankful today with my 12-year-old twins, and at the same time, I keep my love for my two little angels in my heart.

A way forward—Imagining and realizing big possibilities

In 2012, I and two other mothers (together we had five premature babies), decided to establish the first and only Bulgarian foundation for premature children – “Our Premature Children Foundation”. We are strong and we have changed so much in Bulgaria including providing information about prematurity and how to support babies and families in the NICU. Our

foundation gives hope, and help to families, healthcare professionals, and babies. Now there are family rooms in hospitals, we have created a resource booklet for parents, and we speak the same language with the doctors and healthcare professionals.

Our Premature Children Foundation is the first non-governmental organization founded in support of Bulgarian premature children and their families. Our mission is to make a difference for those babies and make sure they have the best possible chance of survival and of reaching their full potential.

What we do

- Raise awareness about preterm birth and possible complications.
- Partner with the government in terms of improving the situation of mothers and newborn babies in Bulgaria as well as initiating constructive dialog with political leaders.
- Establish a network of experts, international and private sector organizations, officials, celebrities, media, business partners, and parents united by the idea of ensuring the best start in life for all premature and sick babies.
- Provide easy-to-understand information and make sure that all families have access to it so that we help them better understand the situation that they are dealing with.
- Facilitate medical and psychological support for affected families.
- Support families through our website, social media, publications, and events.
- Local support groups with volunteers and psychologists.
- Online consultation with psychologists.