

Nina

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[Story Submitted by: loes1263](#)



JUNE, 28 2002. I was 38 weeks pregnant and in the afternoon I don't felt well. It was a strange feeling; I still can't tell what the feeling was like. I lied on my bed for a moment, but it wasn't helping me. I went downstairs and watch TV for a while with Cecca. When it was 16.30 hour I had to see the bathroom and when I grab the door handle, I feel a snap in my stomach. When I looked to my pants it was all red. I with crossed legs to the living room and my oldest daughter, Léonie, started to scream. I said to her to stop screaming and to go to the neighbors. André came immediate. He calls 112 and in 15 minutes the ambulance was there. The brought me to the hospital and it was 17.00 hours when I arrived there. They made an echo and I saw her heart beating. Very slow, but she was still alive. Then they took me to the surgery. I got a caesarian. Nina is born on 17.17 hours and she was dead. They revive her within a minute, but then she started to convulse. When Theo arrived in the hospital he saw 12 doctors and nurses around Nina's bed. Theo understands that Nina wasn't ok. When I recover, I laid on an improvised intensive care. A doctor next to my bed and every minute he measured my blood pressure. Later, I heard I had 1 liter left. I got 12 bags of blood. The hospital in Gouda took Nina to Leiden because Gouda had no baby intensive care. On Sunday June, 30 they took me to Leiden, because Nina wasn't ok. And you can see that on the pictures with Stefano and Nikita. Before the nurse brought me to Nina, Theo and I had a conversation with a pediatrician. He told us that Nina had a brain injury. She had an injury on the basal cores. With these cores you can navigate the loco motor system of your arms and legs. Nina couldn't swallow or suck. She should live her life like a vegetable plant. She had epilepsy. She never should walk; talk and she never recognize one of us. Later on she would be spastic. When I saw her later on, I saw a little sick girl on variety of apparatus. So small and ill. The apparatus watch over her hearth and breathe. She couldn't breathe by herself. On July, 3 I went home and Nina had to stay in Leiden. We went to see her every evening and sometimes during the day. One day I got a phone call from the hospital. The nurse told me that Nina drinks al little bit. They had to hold her in a special position to let her drink, but she did it. I was so glad and thought: 'Now we have to wait, what she is going to do with the rest'. Nobody could tell us more, but I believed in her. I was very positive and Nina felt that. Father 2 weeks Intensive Care, Nina moves to High Care. She drunk by herself in a special position, but that doesn't matter. Nina lost the apparatus which gives her air. Now she breathes by herself. She was tired very quickly, so the rest of the bottle went by stomach pump. On July, 15 Nina came back in Gouda. It was easier for us to go to her. Cecca saw Nina for the very first time. In Leiden she may not go to Nina, because she hasn't had the chicken pox. She still had difference medicines for epilepsy. Phenobarbital and luminal and she had still a tube in her nose for food. On July, 20 she drank for the first time a whole bottle. The nurse draws a big flag on her status. On that page you can see what see had drunk the night before and her weight. One day Nina pulls the tube out of her nose and I asked the nurse to leave it. Nina hated the tube. Since that day Nina drunk much better and she never got a tube again. On another day I told the nurse that Nina did do her best and we were invited for a talk with the doctors. There was a pediatrician, a charge nurse and a doctor. They asked us what we knew about Nina. We told them. They beated a longing of alleviation. They were afraid that the bomb would crack in our family. On august, 1 Nina should be come home, but she was crying for a couple of days and that afternoon she got an insult. She didn't come home. On august 6, Nina finally came home after we made a shopping list of appointments and Phenobarbital for the epilepsy. Nina's first years. Nina had suffered from her intestines. She couldn't discharge. The doctor told us to use a few drips of oil trough her milk, but that doesn't work. After 8 months of worry, we got movicolon and that's works perfect. She still uses it. Nina didn't have any insults at home. In October we had to visit the neuropathies. She told us that we had to try to stop with the Phenobarbital. She didn't tell us that these children had to become totally dry. Nina got 1.8 ml Phenobarbital and every 2 weeks we put 0.1 ml off. 0.1 is nothing, but when you had seen her reaction... She totally tense up. When that happens the first time, I was totally in panic. I called the hospital and had a talk to the neuropathies. She told me that it was normal and I got angry that she didn't tell me about tense up. I told her to tell always the parents what can happen when you stop with medicines. The date we put off 0.1 ml Nina was totally tense up and in the course of the week it gets better. The week after she was better until next Monday when we had to put another 0.1 ml. So we had a bad week and a good week until she lost the 1.8 ml. She got her last 0.1 on December, 31 2002. In October that year Nina also went very ill. She couldn't drink a bottle anymore so I had to feed her with a pipette. I didn't want her back in the hospital with a tube in her nose. She drunk 100 ml and it cost me 2 hours to feed the 100 ml. I carry on with the pipette until January 2003 and one day I thought, I do the milk in the bottle again. Turn on the TV and I'll see what happens. Of course always in the back of my head I was afraid of the epilepsy, but I tried. I laid her on my legs and let her watch The Teletubbies and..... she drunk. Finally! The TV deduces her from the bottle. When she stops drinking, she had 10 or 20 left in her bottle. That what she left, I did with the pipette. Now I was ready in 40 minutes. Now Nina watches TV. When we are on holiday, she goes to live music evenings. Loud music doesn't matter to her. She is only dancing on her manner. When Nina was 6 months old, I could with al lot of difficulty, to make her at laughing. I practiced it every day and one day she makes also noises when she laughs. Nina doesn't have much strength. I practice every day one or two times. Slowly she became stronger, but sit up or crawl she couldn't do it. Her neck was so weak that her head always fall to the left. By much practice Nina becomes stronger, but with her first birthday, Nina still couldn't sit up by herself, crawl or stand. Also we had to think about the future. A highchair for example. I found one. The chair could upward and below. I could topple it when she was too heavy for her. On June, 28 we celebrate her birthday. It was a special day for a special girl. In her second year we kept practice. I did it every day. She got ones per fortnight physiotherapy. That was, of course much too little. But because I practice so much, she makes progress. The doctors in Gouda and Leiden dared nothing more to say. Every time I was there for a visit, Nina could do more things than the last visit. In November 2003 we asked for a walker and a stand-up table, I don't know the right word for it. It's a table where a child stands in. The legs and hip are fixated. I hope someone know what I mean, so that I can use the right word. I thought it spends a few months, but it took 7 months before we had both things at home. When I knew this before, I asked much earlier for device. When you get a child with a handicap, you are thrown in the deep end and you must learn to swim by yourself, nobody told me anything about aid and where and how to get it. You have to find out by yourself.