



Meet Hidde...

Hidde was born in 2011, third in line. The pregnancy had complications and a narrowing in the kidney pelvis of Hidde was found. He received antibiotics for this during the first six months, to prevent a possible bladder infection. After almost 40 weeks, Hidde was born, after a very beautiful birth. Hidde did not look like his sisters and looked into the world with penetrating eyes. The first year we noticed that Hidde almost always moved. He turned his wrists or ankles and often made repetitive movements. He also kept eye contact for a long time and always wanted a "line" with us. That gave and still gives him a sense of security ... "Do you see me?"

Hidde's physical development went well, he quickly turned around in the box, sat down and stood quickly. But he got stuck in cries and did not say many words. The doctor thought he had fluid behind the eardrums and so we went to the ENT. That turned out not to be that bad, but he noticed that Hidde had abnormal ears, thickened ear cups. That in combination with the kidney abnormality meant that we had to look further at that and so we ended up at the UMCG, dept Genetics. The investigations were very difficult, Hidde meanwhile had unpleasant experiences in the hospital and was no longer involved in anything.

After half a year the blood test did not reveal anything special in the genetic field and they wanted the blood to be tested again in a thorough test. This would take a good year. We thought that was fine and just kept on helping Hidde as much as possible.

In the meantime, we had started with speech therapy and EMDR for the traumatic situations in the hospital. He found both very exciting, but once he was used to the supervisor it went better. If my husband or I were in the neighborhood, he kept his "line" and then did better. We had started at the playgroup in the village, after a difficult start-up, the leader and I decided that I would stick with it. It was very noticeable that Hidde did not join the group, had trouble with the rules and constantly needed confirmation and attention. What also stood out was that he had a lot of trouble (and still has) with the emotions of others. He then got involved with the situation, got angry, started throwing things or started to cry.

After a referral, a youth care counselor came to see him, who worked at a Medical Orthopedic Daycare Center. We all agreed that it would be better for Hidde to go to the MOD with more specialist support and smaller groups.

We have built it quietly in terms of hours, an excellent place but an inconsolable Hidde. How hard it was to be there without his parents. It was a fitting place in terms of dear companions and that really helped him through it.

In the meantime, we got the results from the UMCG, Hidde has a genetic disorder called FOXP1.



We had never heard of it and it turned out that it is very rare. What can you expect? The children with this syndrome often have an intellectual disability, a speech / language deficit, behavioral problems and / or physical disabilities. This was a shock, but finally gave an answer to the question from us and everyone around us ... why does Hidde show this behavior of unpredictability, fear, sometimes aggression, repetitive actions, slow speech development and strong dependence on us to take action?

At the MOD it became clear that Hidde indeed had a lowered IQ and that he had to go to a special school after his fourth year. Our oldest daughters first went to our little village school and Hidde had to go to town for education. This has had a major impact on us, because Hidde had few contacts with the children in the village after school. This would only diminish because now that he is older, the differences between him and the other children his age are very large.

Hidde is now 7 years old and still goes to a good special school and is taught there at his level. The behavioral difficulties remain the most difficult. He is often a happy, sweet doll with attention for everyone, but it can suddenly change, especially if he feels that he is not in control of the situation. He can then become aggressive, stuck in saying nasty words. Punishment makes it worse and distraction usually works. That is the strategy that we carry out as much as possible, from the perspective of love and safety we are his safety net, pad and translator for everyone around him. This is true in the family, in the village community and other situations where there are more people. Hidde is very happy with his sisters, who are so sweet and patient. They are 16 and 13 years old and often find it difficult and then withdraw themselves. Hidde has a big stamp on the ins and outs of the family. Eating together or shopping can be too difficult. Even being out of sight of one of the parents can already escalate things because he has lost the line.

This remains the most difficult thing for us to deal with, the pain it causes when your child becomes anxious and therefore shows unwanted behavior. Also the fear that it will be misinterpreted by others. It also requires a lot from us, he always needs 1 on 1 guidance. We are his eyes and ears and always try to be one step ahead of him. For example, it is not traffic safe. We live on a farm with many dangers, but also a lot of space and tranquility. Especially being outside is good for him, throwing stones in the water for hours, looking at the animals and hugging, on the back of the bike, in the forest or swimming in good weather. He has to keep moving a lot, because he has an immeasurable energy.

We are lucky that we live like this, with space, animals and greenery. With a very sweet family who always support us and sometimes relieve us. With good friends and a village where everyone knows Hidde and knows what is going on, we try to be open about that. All this is a great situation to help Hidde in his development as much as possible so that now and later he may find happiness in what he likes and where he feels safe. That is primarily our goal! This sometimes means that we also book a holiday without Hidde, because we can go out for dinner or shop with our ladies and to relax. First with a big lump in the throat, because it is very confronting. It is not a "normal" situation and you do not feel complete. But to be honest, our situation is not normal either. It's very much about Hidde, that's just the way it is. But with some adjusting we all deal with it and I am happy that this process went so smoothly and also happy that there is a diagnosis so that the question "why?" could be answered.

