



Who is Pippa?

Pippa was born at 38 weeks and a few days after a normal pregnancy. We immediately noticed at birth how much she looked like her brother Sam. The APGAR score was good and we were very happy. After a day we noticed that Pip didn't open her eyes much, but the pediatrician didn't think it was worth mentioning. After two days we were allowed to go home! What a party! We kept noticing that Pip didn't open her eyes much, but hey... it must be nothing, we thought. Breastfeeding was difficult but after a few weeks we seemed to find our rhythm. Although she sometimes snored like a pig, which made it difficult for her to drink, she grew well.

After three months, we noticed that Pip started to look more cross-eyed, this was also confirmed by the pediatricians office. This is where the medical rollercoaster began. We've been to several ophthalmologists, no one could tell us what was wrong with Pippa. Maybe she's just a little late? We can now dream of this sentence.

Pip continued to develop steadily but everything went a bit slower. Anyway, if you cannot see properly, you also miss development opportunities and again we were 'reassured', with the conclusion; maybe she's just a little late. The neurologist was the only one who was concerned, despite a good MRI. Furthermore, the rest (pediatrician, orthoptist, ophthalmologist, geneticist) thought that there was as yet no cause for concern.

After a year of uncertainty, we still requested a first test from the geneticist. Despite the fact that she saw no reason yet, we still had the gut feeling that she was not just late. She called back in the middle of summer, well, I don't have that good news. Pippa has FoxP1 syndrome.

Very unknown but it sounded very intense. Problems with speaking, autism, intellectual disability - you really don't want to hear these words. The ground literally sank from beneath us. During this conversation we tried hard to have some clarity, but our geneticist was unable to answer any question. All she said: we had to take into account that Pippa could never live on her own. Bam! This was the beginning of our emotional rollercoaster.

The beginning of living loss, because our vision of the future changed completely in one split second. Will Pip ever walk? Are you going to talk? Are you going to be mentally disabled? How about her brother Sam? We have tried to read as much as possible about this condition in the shortest possible time. What a hell this search was. Actually, we wanted to read that it was all going to be okay... those stories seemed to be there, but were very limited.



We were angry, sad, and insecure and helpless. At the same time, we also felt guilty towards Pippa. She actually didn't deserve the FOXP1 stamp, because she did (and does) very well. We see her struggling and constantly trying. Giving in to this stamp feels like giving up on Pippa and we didn't want (and don't want to) that.

We soon came into contact with the parents of Fenn, the founders of the Foundation Child Well (Stichting Kind Beter). A warm friendship developed. In addition, they taught us the ins and outs and we were introduced to Fenn, what a sweetheart! They also told us about their dream to improve the lives of the children with FOXP1, what a great initiative! We are now doing what we can to support Stichting Kind Beter in this.

Pippa is now 2.5 years old and she is exploring, walks and babbles a lot. She is now attending a fantastic medical daycare center where she receives speech therapy, occupational therapy and physiotherapy, among other things. Dealing with the uncertainty of what our future will bring is still there and at times it takes us by surprise. For us, the new normal has taken on a completely different meaning.

We started with the question who is Pippa, and we haven't actually answered this yet. Because Pippa is not FOXP1. Pippa is a very sweet girl who enjoys contact. Because she finds many things exciting, she always likes to see which way the wind blows, but fortunately her will to discover is greater. It is also a tough girl with a nice temperament, which helps her achieve the things she wants. Pippa taught us that there are little miracles that need to be seen. Every step she takes in her development is celebrated. We help her with this as much as possible. We have learned to look small, to look at her and us as a family. The picture doesn't have to be perfect to be happy.

