Kind Beter

Meet Fenn!

Fenn was born after 36 weeks of a tough pregnancy and an intense delivery.
His first APGAR score was low and the second was even lower. Luckily the third score was a bit better.
To be born with a vacuum pump after 24 hours, with a triple neck entanglement, which made it impossible to come into this world on your own... it didn't start out quit smoothly for our little guy.
But after a few days, we were ready to go home and everything seemed normal.

The first months were quit a rollercoaster for us all. My father was unexpectedly diagnosed with terminal liver cancer and he died just 2 months after Fenn was born. The first months therefor passed in quit a daze.

After a while we all noticed that Fenn was easily scared and anxious. Every sound, every touch could make him tighten every muscle in his little body. He also did not meet any of the normal baby milestones; grabbing toys, making a sound, roll over. None of those were even slightly there. Swallowing was hard, sleeping during the night was a disaster, he had numerous ear infections and at five months he was in the hospital with a RS virus infection.

So, things did not really develop as they should, but we were not really worried.
We thought it was just a case of being a bit behind in his development and a case of some bad luck with the infections.

Until Fenn turned 8 months and we were referred by our physician to a neurologist. Fenn developed a strange kind of seizures, where he would be completely strained, was unable to make contact and would perspire enormously. A complete medical circus started....
In the first year all medics thought of brain damage due to the tough start with the delivery, but nothing was found to prove this.

After numerous checks with the neurologist, the geneticist, our physician etc., we got our diagnoses around the age of three years old. "Well, we finally found something"; we were told in a phone call.

Fenn has a genetic mutation on the FoxP1 gene. Approx. 100 children worldwide and 5 in The Netherlands were diagnosed at that time.

The only answer they could give us when we asked what this would mean was;
"Developmental delay and mental disability, but we really do not have any answers, because we simply do not know much about this rare genetic disease. He just has a little baking error. He probably will never walk or talk. We just do not know. We wish you all the best and have fun with him".

There you are?! And now what? All your dreams and expectations of a normal life are out of the window. Days, weeks, months of disbelief, silent grieve, anxiety and searching on the internet followed.

Cancelling the "normal" daycare center and giving up on a normal school were such difficult tasks. Looking into the world of special schools and be confronted with all these different special needs children was so extremely difficult for us. Was this our future?

Not knowing what the future will bring, gave us a really difficult time.

Hospitals, physical therapy, speech therapy, ENT doctor, neurologist, they all became common to us.

Autistic characteristics which made it impossible for us to simply make a visit to the hairdresser (hair and especially cut hair makes Fenn feel sick). Just go to the dentist (the anxiety clinic is the only option to treat Fenn).
You learn to deal with everything and find you own way.

But it's never easy… but still, within the year's, things did become a little less tough…

For a number of reasons;

1. We adjusted our expectations.
   If you expect nothing things can only be better than expected.
   We do not know if our son will ever walk. …so, when he takes his first steps. Get ready to party!
   And that it took him 2 to 3 years to really get the hang of it, no problem.
   We don't know if he will ever be able to speak. As soon as he pointed at our table and said "tata" and addressed the chair as "air" when he was 4 years old. Champagne!
2. We were able to find a special school where Fenn can just be who he is and learn in his own pace.
   There are children that can learn easier than Fenn but there are also kids that he can help. The fact that he is absolutely in the right place, brings so much peace
3. Fenn is always a happy boy!
   He is beginning to experience that he is different than other children his age;
   He falls a lot and has to get up again, people cannot always understand his speech, kids don't allow him to play along, he is not potty trained yet, he rides a bike with large training wheels on the side, he is not able to hold a pen properly, he has a lot of ear infections, there are a lot of hospital and doctors' appointments.
   A lot of reason to be unhappy or frustrated….. But not our Fenn.
   He is almost always so happy and cheerful! Everyone who meets Fenn is absolutely in love with him right from the start. His sweet smile, his polite 'thank you's', his never-ending optimism and the constant cuddles … he just wraps everyone around his little finger.

Along the way, Fenn is almost 7 years old now, he learned so much, but the difference between him and a normal little boy of 7 is big and will only get bigger as the years go by.

There are a lot of different symptoms that children with FoxP1 suffer from. Our Fenn is so lucky to only have a mild variant of the syndrome. He does suffer from all the symptoms, but all in a mild way.

We can only hope that he will continue to be so open-minded, optimistic and cheerful. This will be a great advantage in the rest of his life. We can only give him all our love and help him to function as independently as possible. That is all we can do, for now…..

But how great would it be if there is a solution/cure for the small genetic mutation that creates so much hassle in his life. This is and will continue to be our dream! And because of our Foundation Child Well and the research program that was set up, this dream could come true!

Not for us or because Fenn is not absolutely perfect the way he his, but for him, for our sweet, brave and fierce full, never giving up, little guy! To give him a life that is a bit easier.