

This update was written in July 2007, when Lizzy is 9 years and 3 months old.

A sweet girl

Lizzy is a very sweet girl. She's very caring and helpful, but only if it comes up in her own mind. When she wants to, she cleans the bathroom, helps her brother Patrick, does the dishes etc. But when she's asked for instance to lay the table, she refuses to do so. She prefers playing with dolls (her baby's) to playing with Barbie's. One can treat dolls as patients, put plasters or bandages on them, with Barbie's you can't. She is also very fond of a girl in our street. This girl is 6 years old and has Downs Syndrome.

Sport loving girl

Lizzy loves to do all kind of sports. She has 3 swimming diploma's, just started her 2nd series of tennis lessons and registered for her 3rd series of inline skate lessons. Actually she likes to do almost every sport, even though she's not an ace. She has to work hard to achieve some results and isn't very athletic. But that doesn't discourage her at all. If she has the chance to register for a sports event, she will and joins in very enthusiastic (for school she attended amongst others peanut ball, ice skating, run-for-fun 3 km marathon and handball). She still loves to be a girl scout and likes (almost) everything they do there.



School

Lizzy was promoted to group 6 of elementary school with average grades, but her first CITO-test results were far below the average. In general she's doing fine. She had some extra support at the beginning of this school year on multiplication tables and she had remedial teaching once a week to improve her technical reading. Her teacher knows Lizzy has Trisomy X. When she starts a new grade, I make an appointment with her teacher and explain about Trisomy X. I tell them I don't want her to be treated like some kind of patient, because she isn't. But if some problems occur, we can support her as soon as possible. She had some emotional outbursts at school if she didn't know how to handle the situation (she starts to scream very loud and then locks herself up into herself, sometimes she cannot be reached for an hour or so). She also has some very impulsive behaviour if she doesn't understand things. In those situations she cannot keep the rule to put a coloured card on her table and wait for the teacher to ask what she wants, she instantly says very loud "I don't understand this".

In a covering letter to the Audiologic Centre where Lizzy's hearing was tested (Lizzy always complains that she cannot hear well enough and wants to sit in front of the classroom to hear better), he teacher wrote:

"Lizzy is a lovely, quiet girl. In the classroom she is distracted easily, which sometimes enables her to finish her work in time. But her concentration is improving.

It is conspicuous she doesn't do her tests as well as I think she can. Afterwards, when I ask her a question from the test again and she has the chance to think about it, she almost every time comes up with the right answer, but she failed to answer correctly in the test.

I believe her test results are not representative for her.

I also noticed that one moment she knows something very well, the next moment she doesn't seem to understand the same thing anymore and a day later she remembers everything again. For instance sums in arithmetic. At first she made 17 out of 20 correct within the time limit. A few days later she scored 7 out of 20 within the time limit (the same sums). And then she had a 100% score within time limits doing sums that were more difficult. So she must have the knowledge, otherwise she wouldn't have been able to score 20 out of 20. It looks like she has the knowledge, but cannot reach it every time she needs it."

Hearing

Lizzy keeps saying she doesn't hear well and prefers to sit in the front of her classroom even if her friends sit in the back of the classroom. That's why I went to the Audiologic Centre to have her hearing tested. The tests show that her normal hearing is fine, but that she doesn't hear well when there are other noises around her. She had some auditory processing problems.

I'll try to describe the final results of the testing in English, which is hard, so I hope this will make sense.

Conclusions (finally came in may 2008)

Lizzy's ears are working fine, her hearing is alright.

She does have problems understanding speech in noise, it's hard for her to separate speech from accompanying noise.

Her IQ is about 95.

Understanding the meaning of words and her passive vocabulary is weak, her active vocabulary is moderate.

In certain tests she makes systematic clerical errors.

Her technical reading is average, comprehensive reading is weak.

Reading nonsense words is above average, reading meaningful words is below average. This means that, if she has to read something without having to think about the meaning of the words, she does fine, but as soon as the words have a meaning, thinking what that meaning is takes a lot of time. This test shows she is not dyslectic.

Instructions in 3 parts are difficult for Lizzy (first do this, then that and then another thing is too much too fast and hard to remember).

She probably misses a lot of instructions in school, because she is distracted easily or because things simply go too fast for her.

Words enter her head, but she is not always able to put the words away in the correct parts of her brain, which causes a lot of searching.

She speaks in short sentences and doesn't say much during tests or in the classroom.

It's a bit like: When somebody asks me something in French, I understand the question, but I cannot find the right French words quick enough to give an answer in French right away. After a few minutes I know what to say in French, but then it is too late. Lizzy has this problem with her native language.

Lizzy is very intent upon her work, she's not easily discomfited, but she should let her teacher know what she doesn't understand, so her teacher can anticipate.

Considering her abilities she is doing great at school!

General advice

We started speech therapy in a thematic way, to make it easier for her to put the words in the right corners of her head. She needs to make better connections in her head to get quicker access to her knowledge. We'll have to keep on checking if she really understands what she is reading. When we study together, I read the chapter and Lizzy has to stop me every time there is a word she doesn't understand. Then I'll explain it to her. This is a good method, if she studies on her own, she reads it, says she understands, but she actually doesn't.

Pediatrician

We went to see a pediatrician for the first time last year. She has had some 'complaints' that might have a hormonal cause. When she was a baby there was a membrane in her vagina that closed the opening. This was treated with hormone cream. When she was 5 years old she has suffered from inflammation of her nipples a few times a year. It looked like it were milk glands, but she was far too young for that. Now that she's old enough, she doesn't have those inflammations anymore.

And now she sometimes has some loss of blood, but it's not clear what causes it. At first I thought that she started her periods, but that is not the case. She had all kinds of testing, they looked for inflammation of the bladder and enteritis, they tested her blood and she had to take laxative medication for several months and she had some kind of scan.

They didn't find anything wrong and the loss of blood disappeared. We stopped the medication and she's fine now.

Her pediatrician was a specialist in chromosomal abnormalities, but he didn't know one bit about Trisomy X. I keep finding this strange. Trisomy X has an incidence of 1:1000, which means that in The Netherlands alone there must be over 8.000 women/girls with this syndrome.

Lizzy knows she has Trisomy X

I thought it was necessary to tell Lizzy about her having Trisomy X for more than one reason:

1. I am busy with the contact group and the website www.triple-x-syndroom.nl. Lizzy's story and photo's are on it and there was an article written about her in Patient Care (a magazine for doctors in The Netherlands) and a chapter in a book on Clinical Genetics. I didn't want her to find out by accident, I prefer to explain it to her myself.
2. When I take her to a doctor or the Audiologic Centre, I don't want to send her out of the room when I have to inform him/her about Lizzy having Trisomy X.
3. I want to support her as well as I'm able too, without mysteriousness.



So I told her she has a chromosome disorder. I kept the explanation very simple. I told her that everybody has many, many small cells in their body and that every cell usually contains 46 mini cells. There are people who have mini cells that are a bit broken, which makes them handicapped (like her brother). Some girls like her have an extra mini cell. That doesn't make her handicapped, but it makes her a bit different from other girls in some ways. So instead of 46 mini cells she has 47.

She listened to my explanation and then she continued her computer game. Sometimes she asks me "What is it again that I have?" or "How many mini cells do I have again?". She also told a friend that she has 47 cells instead of 46 in the same way like she would have told her friend that she had a small cut in her finger or so.

Lizzy is doing fine!

Even though by reading the above one may think that Lizzy's health is a problem, we don't see it that way. She actually doesn't have too many problems with it herself, except the hearing part.

We think she is a great kid and are extremely proud of her.

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After summer holiday Lizzy will start using solo equipment at school. She will put on a headphone when the teacher gives instructions and the teacher will have a transmitter. That way Lizzy hears the voice of the teacher without being distracted by other noises in the classroom. She has tested it for 6 weeks already and says it's great for her. The other kids in her classroom do not treat her any different because of this at all. She is promoted to group 7 now. She stopped her inline skate lessons and will start judo lessons after summer holidays.

Thea van de Velde
Contact group Triple-X Syndrome
Langsteek 15
5641 NG Eindhoven
the Netherlands



www.triple-x-syndroom.nl
www.triple-x-syndroom.nl/english
www.triple-x-syndroom.nl/deutsch
www.triple-x-syndroom.nl/francais
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