

Language skills and speech problems

Many girls with Triple-X start to speak a bit late and will need speech therapy. More often than average they have to deal with dyslexia and/or expressive language problems (finding the right words) and central auditory processing disorder.

Physical issues

In general there are no physical complaints, but Triple-X girls more often than average have to deal with:

- sensory integration issues, like for instance not wanting to wear tight clothing, having problems with stitching in socks etc.
 - unexplained abdominal pains
 - dental problems, such as 'disorderly' position of the teeth, thick enamel layer, some permanent teeth cut through late or not at all.
 - epilepsy
 - urinary passage problems
 - back problems, caused by tall stature.
- However, these are all non specific characteristics!

Mental issues

Girls with Triple-X often have low self-esteem; they are not self-assured and therefore often have problems dealing with persons that have a dominant nature. A positive approach helps them to build up self-confidence, as well as attending self-defence training or assertiveness training. Triple-X girls/women seem to have a slightly increased risk than average on developing depressions and other psychiatric problems.

Parenthood and fertility

The majority of women with Triple-X Syndrome have no problems getting pregnant. Furthermore they seem to have just as much chance of having healthy children as other women.



Contact group Triple-X Syndrome

If you want to know more about the Triple-X Syndrome, you can find more information on www.triple-x-syndroom.nl, the Internet site of the contact group. Contact group Triple-X Syndrome is managed by Ida Bakker & Thea van de Velde, both mother of a Triple-X daughter.

If you join the contact group, you can get in touch with other parents of children with Triple-X and grown women who have this chromosome aberration themselves.

Digital newsletters will keep you informed about recent developments on this subject.

You can join the mail groups set up by the contact group and take part in meeting days. There also are Triple-X mail groups in English, hosted by Yahoo.

We are very grateful to the medical specialists who give us support:
Prof. Dr. C.T.R.M. Schrander-Stumpel (clinical genetics, Department of Clinical Genetics, Academic Hospital Maastricht, The Netherlands),
Prof. Dr. L.M.G. Curfs (psychologist, Department of Clinical Genetics, Academic Hospital Maastricht, The Netherlands),
Drs. M. Otter, psychiatrist, who has examined and treated adult Triple-X women in his practice.

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The information in this leaflet has been gathered from various sources, such as publications of doctors and research workers who have studied and described this syndrome. The personal experiences of parents of girls with Triple-X and women who have Triple-X themselves however were just as important in writing this article.

Information in plain language by Thea van de Velde & Ida Bakker from Contact Group Triple-X Syndrome. Written in Dutch, translated in English in March 2007. The text has been verified by prof. C. Schrander, professor of clinical genetics, Academic Hospital Maastricht (the Netherlands).

Introduction

People are usually born with 46 chromosomes, which are arranged in 23 pairs. One of these pairs contains the sex chromosomes. Sex chromosomes determine whether a baby is a boy or a girl. Boys are born with 1 X - and 1 Y chromosome (XY) and girls are born with 2 X chromosomes (XX). Occasionally a girl is born with an extra X-chromosome. This is known as Triple-X, also called 47, XXX or Trisomy X.

Approximately 1 in 1.000 girls has an extra X chromosome, but often they are unaware of it. In The Netherlands live about 8 million women which means that approximately 8000 girls/women in The Netherlands have Triple-X Syndrome. Some of these girls have the 47, XXX pattern in part of their cells and a normal 46, XX pattern in other cells. This is called a mosaic pattern. Triple-X can be diagnosed by prenatal chromosome analyses.

What causes Triple-X?

The cause of Triple-X is not known, but in a number of cases there is a connection with the age of the mother. The extra X chromosome may come from either the mother or the father, but the first is more frequent.

What is the impact of Triple-X?

Most of the Triple-X girls and women lead normal lives. They go to ordinary schools, have a job, marry and have children and grow old like others. Nevertheless there are some differences between girls with Triple-X and girls with a normal chromosome pattern (XX). Some of these differences are described in this leaflet.

Please keep in mind that it never occurs that a Triple-X girl or woman has to deal with everything described in this leaflet. These things only occur a bit more than average when you have Triple-X.

Babies

Babies with Triple-X are generally quiet, cheerful, sociable babies. Triple-X babies look perfectly normal, but are a little smaller in birth weight, length and head circumference than average. Their muscle tone sometimes is a bit lower than average, so the baby may be a bit slow to hold her head steady and to sit without support. Some have epicanthic folds, a slightly wider space between the eyes and a flattening of the bridge of the nose

Toddlers

Most children walk independently around the age of 1 and start to say small words such as Mama and Dada, girls with Triple-X usually start doing these things a bit later, at around 18 months. If there is no speech when they are 2 years old, checking the hearing and other developing aspects is recommended. This is an indication for chromosome analyses. Speech therapy is recommended in case of speech delay and unclear pronunciation at this age.

Many girls with Triple-X take longer than average to be toilet trained. Most girls are toilet trained around 3½-4 years of age, sometimes staying dry all night takes even longer. Girls with Triple-X may also be a little slower than average at learning to play cooperatively with other children of the same age. Many girls are very shy and do not perform well in groups. Some have emotional outbursts; if they do not know how to handle a situation, they run away, hide themselves, cry or scream.



At school

When Triple-X girls go to primary school, the majority will experience rather more difficulty learning to read and write, to count and tell time. Early recognition of these problems and remedial teaching when they need it will help the child not to get discouraged. It is useful to take a good look at the specific needs of the child, to enable the remedial or special teaching to be correctly focussed. Research has shown that Triple-X girls often have difficulty remembering what they have learnt recently and that information must be repeated more often in order to be fixed in the memory. Repeating something that just happened is often difficult for them. If teachers or parents react impatiently to these for Triple-X girls very serious difficulties, this will cause anxiety and confusion, which will be counterproductive.

Some Triple-X girls may have problems making friends. This may result in lack of self-confidence, if they find that they fail at many points, where other children of the same age appear to succeed effortlessly. If parents accept the child the way she is, instead of having an expectation of high achievements, the child has a bigger chance of building self confidence. Furthermore Triple-X girls sometimes behave childlike for a long time and are emotionally immature. They tend to take many things literally, have problems reading between the lines and have difficulties understanding jokes (especially if the joke is on them).

Intelligence

When intelligence tests have been carried out on girls with Triple-X, their average score is about 20 points lower than the national average. Within families the intelligence level (IQ) of Triple-X girls tends to be lower than that of their brothers and sisters. It is important to remember that, however people attach great value to it, IQ tests give no information about many other important aspects of character, such as determination, honesty and reliability, which are of great importance in finding and keeping a job. Some girls with triple-X are slightly mentally disabled, some complete an academic study, but in practice most Triple-X girls/women function at a slightly lower level than average.

Growth of children and adolescents

Triple-X girls tend to grow a bit faster between 4 and 9, particularly their legs, but this growth is rarely excessive. Breast development generally starts around the age of 11 and most Triple-X girls start having their periods when they are 13-15 years old.

Education and employment

Many girls with Triple-X go on to further education after leaving school. They often find jobs in practical professions, such as catering, childcare and care for the aged, hairdressing or shops. There is no evidence of a higher risk of unemployment for women and girls with Triple-X syndrome. However, for some girls handling money is problematic.