

For EXtra Special Girls



A Guide to Trisomy X (47,XXX)



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association for X and Y variations.

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For parents

This booklet is written to help you explain your daughter's genetic condition, 47,XXX, also known as Trisomy X, Triple X and Triplo-X. When speaking with your daughter it is important to emphasize that this is a common genetic condition. It is estimated that 1 girl in 1000 is born with an extra X chromosome.

Trisomy X is not an illness and it is not life-threatening but it can have a number of impacts on her life. She will need to be aware of how the extra X chromosome may affect her learning, her ability to play sports, and her growth, possibly causing her to be significantly taller than average.

As the parent, you will need to support her if she faces any of the challenges described in this book. It is best to begin the explanation of this slight difference in her body early in her life, even in pre-school. For young children, there is often no need to say anything other than her body has a few extra "messages", and that speech or other therapies may be necessary to help her.

Whether or not to tell your daughter the name of the diagnosis is a matter for your judgment, based on her maturity. When discussing genetic information with her, it is always important that you provide truthful information. The extent or complexity of information can increase as she becomes old enough to understand it.

If she has learning disabilities, or emotional difficulties, your role as a parent in supporting her is critical. Help her to advocate for any special education services that she may need. Assist her with finding hobbies and sports that she enjoys and that give her confidence.

Let her know that even though she may be maturing more slowly than her siblings or peers, she is a valuable member of the community and that you will help her to become the most successful person that she can be.

Girls with Trisomy X usually go through puberty normally. If your daughter also has a Turner (45,X0) cell line, there may be lowered fertility. Some women with Trisomy X experience ovarian failure or premature menopause. This is something to discuss with an older girl. You may also want to mention to a girl who has begun menstruating, that she should tell you if her periods seem to be irregular or for any reason cause concern. It is important that her physician should be aware that she has Trisomy X.

This booklet is meant to be used along with the guide, *Living with Klinefelter Syndrome, Trisomy X and 47,XYY*. The guide provides parents with current information on 47XXX. Pages 32–42 of the guide discuss in detail disclosing the diagnosis and how to talk with your child. As she matures, read appropriate portions to her, or let her read sections on her own and discuss them with you.

What is Trisomy X?

Trisomy X, also known as 47,XXX, is the name of something called a *genetic condition*. In this genetic condition a girl has an extra “X message” in each cell of her body. Trisomy X is common. One girl out of every 1000 girls has an extra X chromosome.

What makes 47,XXX, a chromosomal variation is that it gives you 47 chromosomes when most people have only 46. 47,XXX, is not an illness and it will not make you sick. It is caused by an extra X chromosome, which is one of the many messages in your body that tells your body how to grow and develop.

What are chromosomes and genes?

The tiny structures in your body that determine how you develop and grow are called *chromosomes* and *genes*. They are so small that you need a microscope to see them.

Most girls have two X chromosomes. Your body has three X chromosomes.

Each chromosome has many genes and each gene has a separate function, helping to determine how tall you will be, how you speak, how you see, how your muscles function, and how your brain works. We can think of them as holding messages for the body, telling it how to work and how to grow.

Genes are composed of DNA, which you can think of as an instruction book telling our bodies how to grow and develop. Genes are packaged in our body as chromosomes. The drawing below shows a chromosome composed of many different genes.

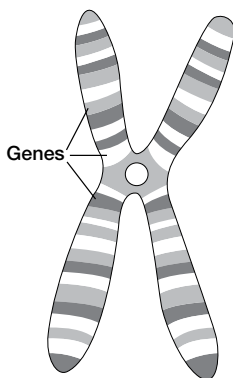


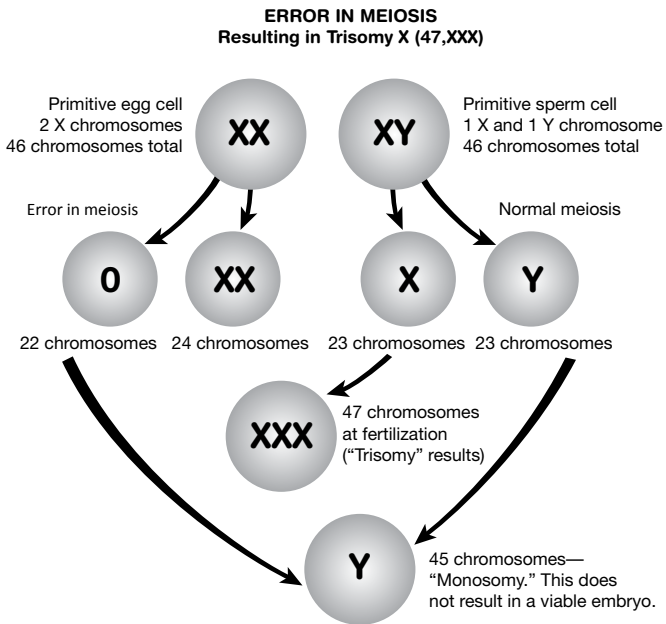
Illustration of an X chromosome. There are more than 1500 genes on the human X chromosome.

How did this extra X chromosome happen?

The extra chromosome happens when the chromosomes divide to create either the egg (from the mother) or the sperm (from the father). The egg and the sperm combine in fertilization. This creates the tiny embryo that becomes a baby.

No one knows why the chromosomes can sometimes become “sticky.” Instead of mom or dad passing down one chromosome from each, a second chromosome also gets passed on to the embryo. Your mother or father could not have prevented the extra chromosome.

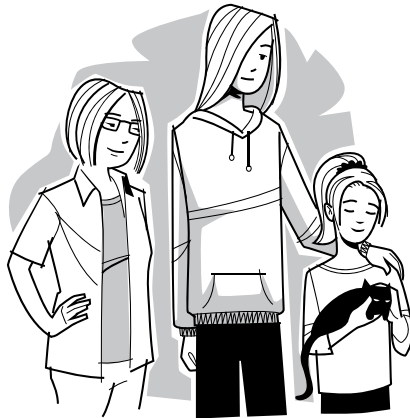
This is a very simple drawing of what happens when an error, called non-disjunction, results in an extra chromosome at fertilization.



How does the extra X chromosome affect growth?

In many girls with 47,XXX, the extra chromosome causes them to be a bit taller than average. Sometimes they are taller than many of their classmates, or even their mothers.

But this is not always the case. There are also girls with XXX who are short.



How does the extra X chromosome affect development?

All girls with Trisomy X are different, just as each person is different. Some girls with Trisomy X do not have any signs or symptoms and learn to speak, crawl, and walk at the usual times. Other girls, however, may speak at a bit later age. If you find that it is hard for you to say what you mean, you may be able to get additional help in school or from a speech therapist who can help you form words and make sentences.

When school starts, some girls with Trisomy X will find it difficult to learn to read, write, or do arithmetic and algebra. This is because Trisomy X can affect the way your brain processes words and numbers. It is not because you are lazy or not trying hard enough! It just means that you and your parents and teachers need to find another way for you to learn. It may take longer for you to learn to do some things.

Schools are required to make a plan to give extra help to you if you need it. An example would be a 504 plan to give you extra time on tests. Another type of assistance is in an Individualized Education Plan, called an IEP.

As you move into higher grades, you may encounter difficult subjects where you may find yourself struggling to keep up. If this happens, speak with your parents or teachers about additional help.

Many girls with Trisomy X have reported that they do particularly well with music, art, computers, and work requiring a good sense of shapes and distances, such as graphics or clothing design. As you go through school, find those subject areas that you like and where you think that you would be happy working as an adult.

Trisomy X can also impact other areas of your life

Another area where Trisomy X may affect some girls can be in physical activities. If you find that you are not good at certain sports, such as fast team sports like soccer, you can choose to enjoy other activities, like bike riding, or dance, or sailing. It is important for you to explore a number of activities to find sports and exercise that you enjoy. Some girls with Trisomy X find that their muscle tone and balance are not as good as they might be. Weight training, martial arts, dance and yoga are some excellent ways to help you develop strength and balance, and can help to give you confidence.

Another area where you may have concerns is that you may feel shy. Speak with your parents if this is a concern. You can get involved in groups that help you with learning what are called “social skills” so that you can have an easier time making friends. It can also help to make sure that you develop your own interests and hobbies. If you have interests like raising and training animals, music, painting, or other hobbies and activities, it will give you the confidence that you need to make friends.

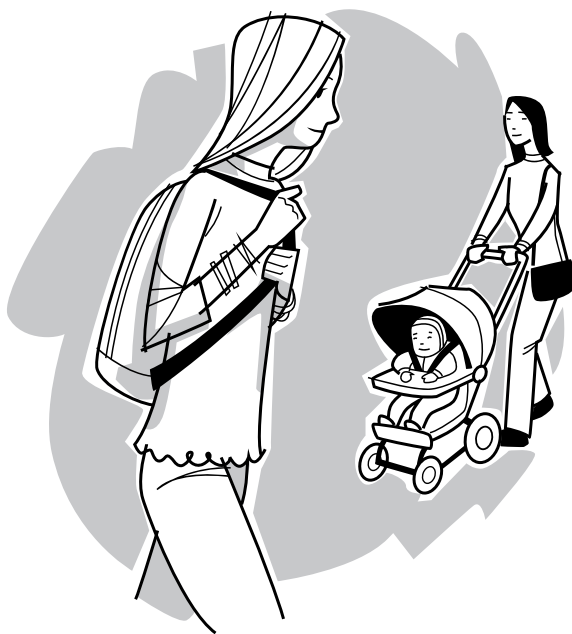


Some girls with Trisomy X feel as though they can get angry too easily. Other girls find that they worry quite a bit about all sorts of things. Having Trisomy X does not mean that this will happen to you, but the extra X chromosome can affect the ability of some girls to keep control over their emotions. If this seems to be a problem, your parents, your school and your doctors can help you to learn to gain control over worrying, or over angry thoughts, and other things that bother you.

If you are feeling worried about school, friends or other areas of your life, it is important for you to tell your parents, a teacher or another trusted adult.



Girls with Trisomy X almost always go through puberty normally. Occasionally a girl with an extra X chromosome may need some extra estrogen, which is the female hormone, but this does not happen very often. Most women with Trisomy X can have babies normally, although some may need some help from a special fertility doctor.



Genetic information is private. There is no reason for you to talk with anyone but your own family and your doctors about your extra X chromosome if you do not feel comfortable doing so.

The extra X chromosome is nothing to be ashamed of, and it is common. But it is a good idea to guard your genetic information, and to talk about it only to people with whom you are very close and whom you can trust. If you fall in love, you will want to tell this person about Trisomy X. Don't give the information to people who may tease or hurt you, or try to bully you because of knowing that you have an extra X chromosome.





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