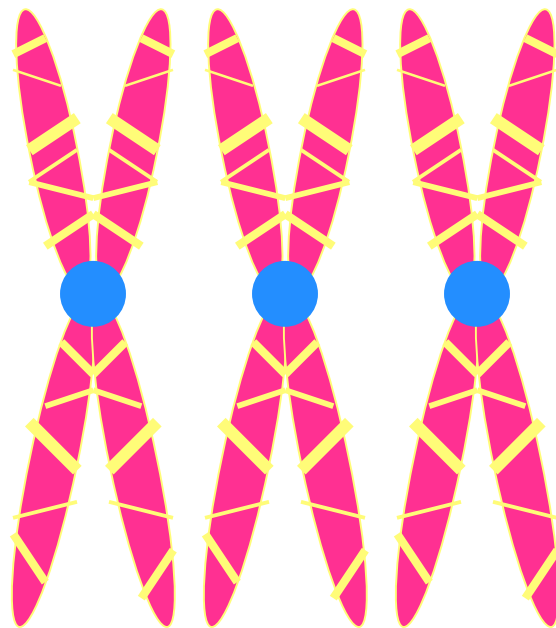


My Guide to Trisomy X



Dear Parents,

The purpose of this booklet is to provide your daughter with age-appropriate information about Trisomy X as well as to assist you in talking to your daughter about Trisomy X. Disclosure is a process, and this booklet can help begin the process or to provide further information as your daughter gets older and begins to ask more questions.

Girls with Trisomy X are individuals and will have their own challenges and strengths, just like everyone else. For this reason, not all of the topics described in this booklet may apply to your daughter. Please use the table of contents to choose the areas that are relevant to your daughter.

In a survey, parents who had already disclosed the Trisomy X diagnosis to their daughters were asked to give advice to other parents who were thinking about disclosing the diagnosis. The consensus was to keep explanations simple, age appropriate, honest, and positive.

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What is Trisomy X?

Girls with Trisomy X have three copies of the X chromosome, while most girls and women have two. Even though this is unusual, it still happens to lots of girls. If you met 1000 girls, 1 of them would probably have Trisomy X. This means that there are over 150,000 girls and women with Trisomy X in the United States!

It is normal for girls with Trisomy X to feel that certain things or situations can be more of a challenge for them. This booklet discusses some of the ways a girl with Trisomy X might feel different, but remember that everybody has strengths and weaknesses just like you. Lots of girls and their families have found that it is easier to work through these challenges when you know about Trisomy X, and what it might mean for you.

We also asked older girls and women with Trisomy X for advice for girls like you with Trisomy X. Look for it in boxes like these!

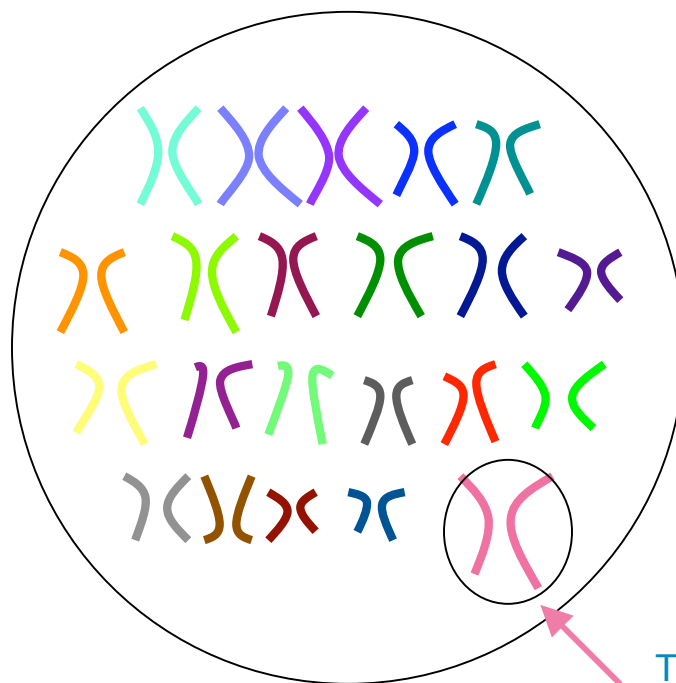
What Is a Chromosome?

Everyone's bodies are made of billions of cells, and inside of every cell are our chromosomes. Chromosomes have directions that tell our bodies how to grow and what we will look like.

Most of the time, people have 46 chromosomes that come in 23 pairs. We usually get one of each chromosome from our mom and one of each chromosome from our dad.

One pair of chromosomes tells our bodies whether we will be a boy or a girl. Boys have only one X chromosome and one Y chromosome. It is the Y chromosome that makes them a boy.

Most of the time, girls have two X chromosomes. Girls with Trisomy X have three X chromosomes.

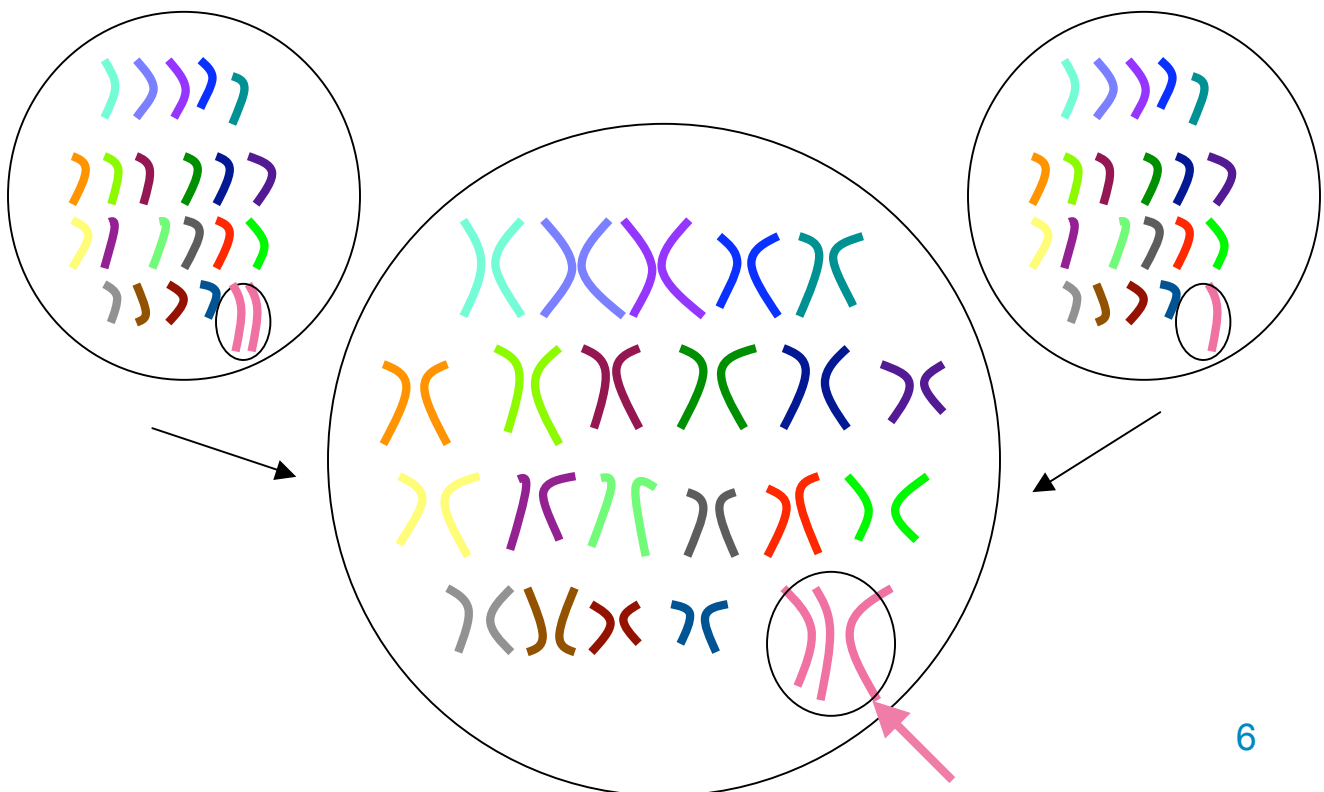


These are the X chromosomes

How Did I Get Trisomy X?

The extra X chromosome has been a part of you since before you were born. Nothing you did and nothing your parents did caused it to happen, so it is nobody's fault. It is not a disease, so you can't "catch it" or give it to somebody else.

Having an extra X chromosome is one part of who you are, and it is not something that can be or needs to be changed. The third X chromosome will not make you sick. Most girls have two X chromosomes, but lots of girls have three. It is very normal!



What does this mean for me?

Height

Many girls with Trisomy X are taller than other girls their age or taller than other girls in their family (you might have already noticed this!). Lots of girls with Trisomy X think this is a good thing!

Being taller is beautiful and very helpful in life.

What does this mean for me?

Movement and Handwriting

Some girls with Trisomy X might have difficulty doing things neatly with their hands, like handwriting or coloring.

Girls with Trisomy X might have trouble keeping their balance. Sometimes they bump into things. Other girls might get tired easily when they exercise or they might find that their muscles are not as strong as other girls.

Exercise and physical therapy can help with your coordination and strength!

Write sentences over and over to help your hand write neatly. Play video games to help your hand coordination. Play a piano.

Clear an aisle where you work, and learn to trail the wall with your fingertips when walking, this is to assure you of having a stable object to touch to help your balance. Walk slowly and watch where you are going, there are times you will feel like you are all arms and legs.

What does this mean for me?

Learning

A lot of girls with Trisomy X have difficulties with learning and might need some extra help in school. This could mean asking for more help from your teacher or other kids in your class, having a tutor, or going to special classes. Try to figure out the easiest way for you to learn- is it by listening to the teacher, or reading about it, or practicing something over and over? Even though it might be difficult at times, it's important to always try your best.

You could be a bit slower than other girls your age but it's a good thing as you can get support and they will help you through it. I'm now reading and writing as a normal 23 year old would be.

Get all the help you can!

What does this mean for me?

Talking with Others

Some girls with Trisomy X have difficulty saying what they want to say. Sometimes, it can be hard to think of the right word. Try to slow down when you talk. If you can't remember a word, try to find a different way of explaining it. Some girls go to a speech therapist for extra help.

Girls with Trisomy X might have difficulty understanding what others are saying to them, which is why they might have trouble understanding jokes.

If you have a phone call write it down before you call the number. Then you won't forget what to say.

Learn the techniques for word retrieval, think out loud, write down what you want to say and practice saying it several times... Consider taking a public speaking class.

What does this mean for me?

Friends

Some girls with Trisomy X aren't sure how to act around their friends or feel like they don't fit in. Try finding an activity you like to do and share it with your friends! It's okay if you feel a little different. Everybody does, some of the time.

Some girls with Trisomy X feel anxious around large groups of people. It's alright if you feel shy in big groups. Try talking to a new person- you might surprise yourself!

It will take work and will be tiring because you have to work that much harder at it (example: being more outgoing) but you will be proud of the progress you made by not allowing xxx to limit you.

I get nervous in large crowds but I know it's my disability causing it. If you get in this situation, calm down and tell yourself you can handle it.

What does this mean for me?

Feelings

Some girls with Trisomy X have a hard time controlling their feelings and might get easily angry or upset. Sometimes it helps to find a quiet place where you can sit and think and be alone when you start feeling angry.

When you feel your temper coming on, do not lash out at people, sometimes "flash anger" can overwhelm us, and we just react. Get counseling for your temper and learn how to release anger in productive ways, like go for a walk, listen to calming music, use relaxation techniques, have some time alone in a safe place, have a special friend to talk to (maybe a pet)... Spend time away from the situation and return when you are feeling calm.

Identify with them and get support when you are ready - if you find them to be overwhelming

Strengths

Remember that everyone is different and has their own challenges. Everyone has to work harder at the things that are most difficult for them. At the same time, everyone has strengths and things they are good at. Many girls with Trisomy X are good at things like art, music, playing with animals, or taking care of younger children.

Try to think of what you like to do and the things that you are good at!

I have good humor and I can make people laugh. I love to play the piano and I taught myself to read notes.

Privacy

Many people have never heard of Trisomy X. Every family has to decide for themselves how and when they want to explain Trisomy X to their friends and relatives. Lots of girls decide that they can tell their friends about Trisomy X, since there is no reason to feel ashamed or embarrassed. Other girls decide they would rather keep the information private because sometimes people don't understand, and they may say things that are wrong or hurt your feelings.

This is something that you should discuss with your own family.

Advice

Here's some more advice from older girls and women with Trisomy X!

It is part of who you are - find a way around the challenge. Be strong - there are a lot of girls out there just like you

Don't let a label define who you are or limit yourself.

Learn all you can but don't let it limit you or dictate to you how you should act. You can improve in those areas - ask your parents for help.

Believe in yourself...the sky is the limit. Set your goals high and you will reach them.