

For EXtraordinary BoYs



A Guide to 47,XYY



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association for X and Y variations.

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For parents

This booklet is written to help you to understand and explain your son's genetic condition, 47,XYY. An important thing to emphasize when you speak with your son is that this genetic condition is quite common. One boy in 1000 is born with an extra Y chromosome.

XYY is not an illness and it is not life-threatening. But XYY can have a number of impacts on his life, and he will need to be aware of ways in which the extra Y chromosome may affect his learning, his ability to play sports, and his growth, because he may be significantly taller than average.

As the parent, you will need to support him if he has any of the challenges that this book outlines. Many boys with XYY have few or no symptoms, while others have considerable challenges.

It is best to begin the explanation of this slight difference in his body early in his life, even in pre-school, especially if he has had speech delays or slow motor skill development, and has required speech therapy or any other special services. For young children, it is appropriate to tell him that his body has a few extra "messages".

If he receives speech or other therapies, you can tell him that they are necessary to help him to develop as all other children do. You do not need to tell a child younger than 8 or 9 what the name of the genetic condition is, but you should always be truthful when talking with your son.

If he has learning disabilities, or if he has experienced some emotional difficulties, your role as a parent in supporting him is critical. Help him to advocate for any special education services that he may need. Assist him with finding hobbies and sports that he enjoys and that make

him feel competent. And let him know that even though he may be maturing more slowly than his siblings or peers, he is a valuable member of your family and that you will help him to become the most successful person that he can be.

This booklet is meant to be used along with the guide, *Living with Klinefelter Syndrome, Trisomy X and 47,XYY*. The book features a thorough discussion on pages 32–40 about disclosure of the diagnosis and talking with your child. The guide will provide you, as the parent, with current information about 47,XYY. As your son matures, you may want to read appropriate portions to him, or let him read sections on his own and discuss them with you.

What is 47,XYY?

47,XYY, is the name of something called a *genetic condition*. In this genetic condition a boy has an extra “Y message” in each cell of his body. XYY is common. Approximately 1 boy out of every 1000 has an extra Y chromosome.

What makes 47,XYY, a chromosomal variation is that it gives you 47 chromosomes when most people have only 46 chromosomes. XYY is not an illness and it will not make you sick. It is caused by an extra Y 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 boys have one X chromosome and one Y chromosome. You have one X chromosome and two Y chromosomes, so you have one extra chromosome.

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 genes 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.

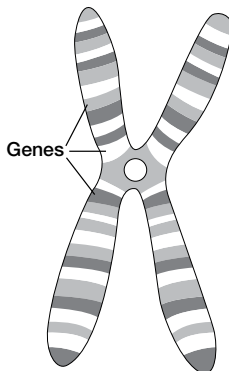


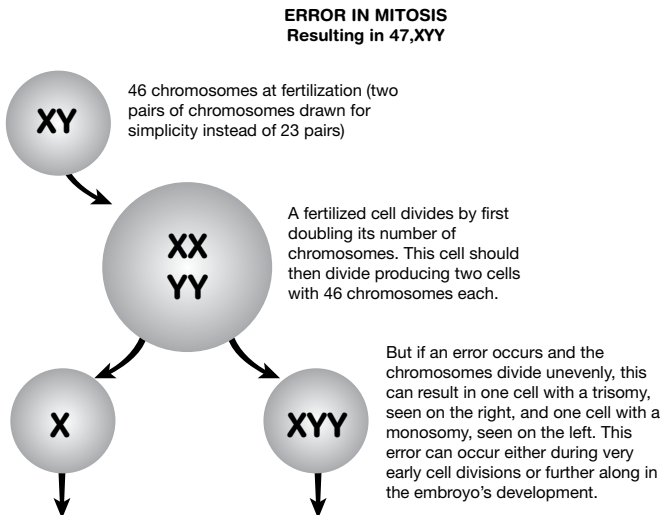
Illustration of an X chromosome. There are more than 1500 genes on the human X chromosome.

How did this extra Y chromosome happen?

The extra chromosome can happen 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” and instead of mom or dad passing down one chromosome from each, a second chromosome also was passed on to the embryo. Your mother or father could not have prevented the extra chromosome. The extra Y chromosome can also happen when there is an error in cell division after fertilization.

This is a very simple drawing of what happens when there is an error during cell division after fertilization resulting in an extra chromosome.



How does the extra Y chromosome affect growth?

In many boys with XYY, the extra chromosome may cause them to be taller than average. Sometimes they are taller than many of their classmates, or taller than their fathers.

But this is not always the case. There are also boys with XYY who are short.



How does the extra Y chromosome affect development?

All boys with XYY are different, just as each person is different. Some boys with XYY do not have any signs or symptoms. They learn to speak and crawl and walk at the usual times. Other boys, 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, many boys with XYY will do well, but for some, it may be more difficult to learn to read, write or do arithmetic and algebra. This is because XYY can sometimes affect the way that 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.

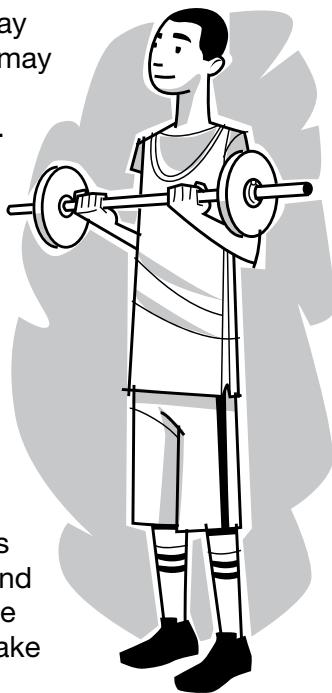
As you move into higher grades, you may encounter difficult subjects where you find yourself struggling to keep up. If this happens, speak with your parents or teachers about additional help.

Many boys with XYY 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 carpentry. 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.

XYX can also impact other areas of your life

Another area where some boys find that XYX affects their lives 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 golf, or sailing. It is important for you to explore a number of activities to find sports and exercise that you enjoy. Some boys with XYX find that their muscle tone and balance are not as good as they might be. Weight training and martial arts are 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 such as fishing, music, repairing computers or cars, or other hobbies and activities, it will give you the confidence you need to make friends.



Some boys with XYY may feel as though they get angry too easily, or that they worry too much. Other boys may have difficulty with avoiding mischief or behavior that they know is not right. Having XYY does not mean that this will happen to you, but it can sometimes affect your ability to control your emotions or your ability to stop and think before acting. If this seems to be a problem, your parents, your school and your doctors can help you to learn to gain control over your emotions or your impulses.

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.



Boys with XYY almost always go through puberty normally. Occasionally a boy with XYY needs extra testosterone, which is the male hormone, but that does not happen very often.

There is a risk of severe acne for teenagers with XYY. If this happens, your parents will probably take you to a dermatologist to minimize scarring on your face and body.

Boys with XYY sometimes have a problem with teeth that decay easily. Brushing your teeth well twice a day and limiting sugary snacks and soda will help you to avoid tooth decay.



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

The extra Y 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 XYY. 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 Y chromosome.





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