What is the cause of XYY?

The usual reason for XYY occurring is that an extra Y chromosome was present in the sperm that fertilised the egg that went on to produce the baby. When sperm are formed, they divide a couple of times and share chromosomes equally among the newly formed cells. Occasionally cells do not divide evenly and chromosomes are not shared as expected. This is a completely random event. It is not caused by being an older parent. There is no known case where anything a parent did or did not do before pregnancy or while they were pregnant caused their baby to have an extra Y chromosome.

Puberty and having children

Puberty is normal in XYY boys although some boys may have enlarged testicular size starting in early puberty. Testosterone levels are within the normal range for most boys. XYY men form relationships, settle down and have children at the same age as XY men.

Telling your child

Deciding when to tell a boy about the extra chromosome is personal, but once a boy is old enough to have children of his own he has a right to know. Many families tell boys in early adolescence. When the time comes, it can be helpful to draw on the expertise of a support group or an expert geneticist.
Other professionals who look after your child are usually best told on a need-to-know basis.

Families say ...

... a gentle giant.
... friendly, outgoing and well-liked.
... an incredible memory for his obsessions.
... a fascinating mind, somewhat off-centre.
... like living with a teenager for 15 years.
... when I was told, I was devastated.
... very much a central part of the family, likes to love and be loved.

Inform Network Support

Unique
Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group,
The Stables, Station Road West, Oxted, Surrey RH8 9EE, UK
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

AXYS
PO Box 872, Pine, CO 80470-0872 USA
info@genetic.org | www. genetic.org
www.facebook.com/groups/AXYS.XYY

Facebook groups

XYY Chromosome Disorder
www.facebook.com/groups/31905218415

47XYY syndrome support group
www.facebook.com/groups/1406286052987882

Unique mentions other organisations' message boards and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it.

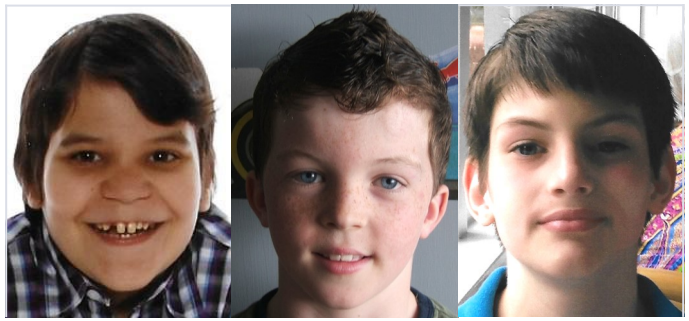
When you are ready for more information, *Unique* can help. We can answer individual queries and we publish a full leaflet about XYY and a study day report. We also publish a booklet for children and a booklet for parents considering whether to inform their child, other family members or other people about this genetic condition.

This information sheet is not a substitute for personal medical advice. Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health. The information is believed to be the best available at the time of publication and the medical content has been verified by Dr Mary Linden, Department of Pediatrics, National Jewish Medical and Research Center, Denver, Colorado, USA and by Unique's Chief Medical Adviser 2004 (Version 1).
Version 1.1 2020 (AP), version 1.2 2021 (AP)

Rare Chromosome Disorder Support Group
Registered in England and Wales
Charity Number 1110661
Company Number 5460413

Unique
Understanding Chromosome & Gene Disorders

Living with XYY



rarechromo.org

What is XYY?

XYY is a genetic variation in which boys and men have an extra Y chromosome. Most cells of our body usually have 46 chromosomes, boys and men with XYY (sometimes called 47,XYY) have an additional Y chromosome. About 90 per cent of people with XYY have the extra Y chromosome in every cell of their body, while about 10% have a mixture of XY and XYY containing cells (this is called mosaic XYY).

What is a chromosome?

The human body is made up of many cells and inside most cells is a nucleus that contains the same set of chromosomes. Chromosomes are made from long stretches of DNA that code for our genes. Genes are the instructions that tell our bodies how to grow, develop and function. A typical cell has 46 chromosomes, 22 'autosomal' chromosomes (numbered 1 to 22) and two 'sex' chromosomes that determine biological sex; girls usually have two X chromosomes and boys usually have one X and one Y.

How is XYY detected?

It has been estimated that 85% of males with XYY have not been diagnosed. They go through life unaware of their extra Y chromosome. XYY may be discovered by chance during prenatal diagnosis undertaken for an unrelated reason. A chromosome analysis of amniotic fluid will show the extra Y chromosome. Some boys are diagnosed by a genetic test offered during childhood normally due to learning or behavioural difficulties.

What are the main effects of XYY?

- Boys and men are often tall
- Intelligence is usually in the usual range but an increased need for educational support especially with reading and writing is apparent
- There is an increased vulnerability to ADHD (attention deficit hyperactivity disorder), and, to a lesser extent although still significant, ASD (autistic spectrum disorder), anxiety and depression
- There is also a possible increased risk of asthma, seizures, tremor and dental problems

Learning

Boys usually achieve intelligence levels within the normal range. One study of 60 boys showed that their average IQ was 105 and the range was 65 to 129; a more recent study of boys diagnosed during pregnancy showed an IQ range of 100 to 147. Compared with their brothers and sisters, most boys with XYY show a slight drop in IQ, but no more than you would expect from natural variation between members of a family.

Stature

Boys may be unusually tall. From an average length at birth, growth accelerates from age two so by puberty boys with XYY are already almost 8 centimetres (three inches) taller than other boys. Final adult height is an average of 188 centimetres (6'2") and some boys are much taller.

Tall stature is common, but few boys are as tall as this.

How common is XYY?

It has been estimated that about one boy in 1000 has an extra Y chromosome, although the majority do not know they have it.

Points to consider

All children thrive best in a secure, loving and stimulating environment where their needs are recognised and any necessary professional help is provided. This is particularly true of boys with XYY for whom such a home can help to compensate for any immaturities and subtle vulnerabilities they may have.

- **Speech** Most boys with XYY start to talk at the expected age, but speech delay is twice as common as in other boys. A home environment that encourages natural conversation is helpful. With early speech therapy, many boys catch up before starting primary school and by the teenage years the speech delay has resolved for the great majority.
- **Temper tantrums** In some boys there is a tendency for toddler tantrums to be severe and long lasting and parenting techniques of avoiding triggers, diversionary tactics and time out may not work. With maturity and more fluent speech these tantrums do fade and most older boys are no more aggressive than anyone else.
- **School** Boys with XYY usually attend mainstream schools but despite their intelligence they tend to need extra support. Some have a degree of learning difficulty but with early support, most commonly with literacy, continuing problems are unusual.
- **Attention** Boys with XYY are naturally active and some find sitting still to concentrate difficult. They do best in an environment where they can be active.
- **Writing** There is a tendency for some boys to be slow at tasks like drawing, writing and cutting. Most catch up with extra practice at primary school but a few advance faster with help from occupational therapy. Access to keyboards and computers can be helpful for these boys.
- **Socially** Many boys have no social difficulties. A small number are awkward in groups and can seem immature, aloof or anxious. School may be particularly trying for them and families benefit from guidance in behavioural techniques and social skills.