What is the cause of XYY?
The usual reason is that when the sperm were forming, the cells did not divide evenly and an extra Y chromosome was left in the cell. 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 completely normal. Current evidence suggests that XYY men form relationships with girls and settle down and have children at the same age as other men.

Telling
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

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Tel/Fax: +44(0)1883 723356
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AXYS
PO Box 872, Pine, CO 80470-0872 USA
info@genetic.org | www.genetic.org | www.facebook.com/groups/AXYS.XYY

More 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. We also have fact sheets about specific aspects of XYY. 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.

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What is XYY?

People usually have 46 chromosomes in each cell in their bodies, including two sex chromosomes. In boys and men, the sex chromosomes are called X and Y. Boys and men with XYY (sometimes called 47,XYY) have an extra Y chromosome. About 90 per cent of them have the extra Y chromosome in every cell, while the others have a mixture of XY cells and XYY cells.

What is a chromosome?
The human body is made up of cells and inside each cell is a nucleus where genes are stored. Genes are the instructions that tell the body how to develop and work properly. The genes are grouped along chromosomes, long structures made out of DNA that look like twisted pipe cleaners when viewed through a microscope.

How is XYY detected?
The great majority of boys with XYY are not detected. They go through life unaware of their extra Y chromosome. XYY may be discovered by chance during prenatal diagnosis undertaken for an unrelated reason such as being an older mother. A chromosome analysis of amniotic fluid will show the extra Y chromosome. A small number of boys are diagnosed during childhood.

What are the main effects of XYY?

Most boys and men have:
- Nothing unusual about their appearance, although they are often tall
- No typical medical problems or illnesses
- Intelligence in the usual range. The average IQ is over 100, but some boys may still need extra learning support
- No problems with sex organs and puberty
- Possibly a greater vulnerability to behaviour problems, including hyperactivity
- Possibly, greater vulnerability to stress.

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 2 so by puberty boys with XYY are already almost 8 centimetres (three inches) taller than other boys. Final adult height is an average 188 centimetres (6'2") and some boys are much taller.

How common is XYY?

Around one boy in 1000 has XYY chromosomes. Most do not know they have an extra chromosome.

Special points

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 in the great majority of boys.

- **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.