Trisomy 13
(also called Patau’s syndrome or T13)

Information for parents
1. What is trisomy 13?

Inside all of the cells of our bodies there are tiny structures called chromosomes. These chromosomes carry the genes that determine how we develop. There are 23 pairs of chromosomes in each cell. When our bodies produce sperm or egg cells, the pairs divide and rearrange themselves. Sometimes these pairs of chromosomes do not divide correctly.

With trisomy 13 there is an extra copy of chromosome 13 in each cell.

There are three forms of the syndrome, as explained below. This information sheet focuses on complete trisomy 13, the most common and most serious form of trisomy 13.

| Complete trisomy 13 | This is when every cell in the body has three copies of chromosome 13. Babies with this condition will have complex disabilities. |
| Mosaic trisomy 13 | This is when some cells have the usual two copies of chromosome 13 and some have three copies. |
| Partial trisomy 13 | This is when there is an extra part of some of chromosome 13 in all the body's cells. |

Complete trisomy 13 is fatal. Babies with partial and mosaic trisomy 13 may survive to adulthood, but this is rare.

All babies with trisomy 13 will have a wide range of problems. Unfortunately these problems are usually extremely serious.

These may include major brain abnormalities leading to learning difficulties. Many babies also have heart problems, a cleft lip and palate, poorly formed eyes and ears, and problems with their arms and legs. It is difficult to say how serious the effects of partial and mosaic trisomy 13 will be before the baby is born.

Although women of any age can have a child with trisomy 13, the chance increases as a woman gets older.

2. How common is it?

Trisomy 13 affects about 2 of every 10,000 births.
Trisomy 13 may be suspected from the early ‘combined’ test for Down’s syndrome because of an increased nuchal translucency (thickening at the back of the baby’s neck).

Signs that the baby may have trisomy 13 may also be noticed at the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy.

If trisomy 13 is suspected, you will be offered another test called an amniocentesis or a chorionic villus sampling (CVS). There is more information on CVS and amniocentesis in leaflets called: *Chorionic villus sampling (CVS) – information for parents* or *Amniocentesis test – information for parents*. These are available on our website at [www.fetalanomaly.screening.nhs.uk/publicationsandleaflets](http://www.fetalanomaly.screening.nhs.uk/publicationsandleaflets). You can also ask for a copy of these from your healthcare professional.

Unfortunately, there is no cure for trisomy 13 as the extra chromosomes cannot be removed.

Most babies with complete trisomy 13 die before they are born or shortly after birth. Babies with partial or mosaic trisomy 13 can live beyond a year, but this is rare. Babies with these conditions still have complex physical and learning difficulties.

Treatment of babies born alive will focus on feeding, treating infections and managing heart abnormalities.

Many babies can be cared for at home with support. You will be offered emotional and practical support.

You will be given the chance to talk to specialists about your options. You will have the opportunity to discuss the possible implications of ending or continuing your pregnancy.

As babies with complete trisomy 13 die before or shortly after birth, you will be offered a termination to end the pregnancy. If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.

If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed. As there is no cure for this condition, doctors will discuss palliative care with you. Palliative care is care aimed at relieving the symptoms of a condition rather than treating or providing a cure. You may be referred to the children’s palliative care team and the local bereavement service.

Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

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3. How is it diagnosed and confirmed?

4. Is there any treatment?

5. What is the outlook for the baby?

6. What happens next?
7. How likely is it to happen in a future pregnancy?

Anyone can have a baby with trisomy 13. In most cases this condition does not run in the family. It is not due to anything you did or did not do.

You are much more likely to have a normal, healthy baby in your next pregnancy than to have another baby affected with trisomy 13.

For complete trisomy 13, the chance of having another baby with this condition is about 1% (1 in 100). The chance of having a baby with trisomy 13 does increase with age, so older mothers will have a higher chance of having another baby with this condition.

You may be offered a chromosome test to see whether this condition is linked to something called ‘a translocation’ of your chromosomes. If this is the case, you will be referred to a genetic counsellor to discuss the chances of this condition happening in another pregnancy. In a future pregnancy you would be offered scans by a specialist as well as tests (chorionic villus sampling (CVS) or amniocentesis) for reassurance and to diagnose any problems at an early stage.

8. Where can I get more information and support?

You may feel you only want to talk to your family and friends, or a particular doctor or midwife from the hospital. However, there are other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and afterwards. You may also want to talk things through with the hospital chaplain or your own minister or faith leader.
9. Further information, charities and support organisations

Antenatal Results and Choices (ARC)
Email: info@arc-uk.org
Helpline: 0845 077 2290
Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.

SOFT UK
Email: enquiries@soft.org.uk
Website: www.soft.org.uk

SOFT UK provides information booklets and support for those affected by Patau's syndrome or Edwards' syndrome (trisomy 13 and trisomy 18), and related disorders such as mosaicism, deletion, ring and partial trisomy:

- whether you have a termination or continue the pregnancy after a prenatal diagnosis;
- after the loss of an unborn baby, baby or child; and
- for parents and carers of a baby or child.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

This leaflet has been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups.

All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

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