

# Cystic hygroma Important information for patients

## This information aims to help you understand more about cystic hygroma.

If you have recently had an ultrasound scan indicating that your baby may have a cystic hygroma, you may have some questions about the condition. This leaflet hopes to address some of these questions and give you information about the condition and what will happen next.

## What is a cystic hygroma?

A cystic hygroma is an uncommon finding that is sometimes seen during the routine early pregnancy scan. It is suspected when fluid filled areas are seen under the skin around the baby's neck. It is thought to develop from a blockage in the baby's lymphatic system. The lymphatic system is a network of vessels that normally drain into two large sacs in the baby's neck. By the end of the 5th week of pregnancy, the baby's lymphatic tissues form as lymph sacs. These eventually join up with the baby's blood vessels. When a problem occurs between the veins and the developing lymph sacs, the sacs expand with fluid and partially or completely block the vessel system.

### What does it mean for your Baby?

A cystic hygroma forms in the first few weeks of pregnancy and cannot be prevented. Nothing you did or did not do during pregnancy caused the cystic hygroma to develop.

The exact cause is unknown. Small cystic hygromas can disappear by themselves, causing no further problems for your baby. However, some cystic hygromas can grow in size and result in 'hydrops', the formation of extra fluid within the baby's body, which can lead to miscarriage (pregnancy loss).

Cystic hygroma is often the sign of a problem in a developing baby.

It may occur on its own or as part of a chromosomal/genetic syndrome, such as Turners syndrome, Downs syndrome or Noonans syndrome.

#### **Chromosome conditions:**

In approximately 50- 60% (about half) of babies, the cystic hygroma is part of an underlying problem with baby's chromosomes. Chromosomes are the part of the cell that contain genetic material from our parents. These abnormalities may affect other parts of the baby like the heart.

The most common chromosomal problem associated with cystic hygroma is called Turner's Syndrome (45X0) affecting female babies only. It can also be associated with other chromosome problems including Down's Syndrome, Edward's Syndrome and Patau Syndrome.

#### Physical problems:

Babies with a cystic hygroma are also more likely to have unexpected physical findings in other parts of the body. Heart defects are the most common type of problem found, but many different types of problems have been reported.

#### **Genetic syndromes:**

There are many different genetic syndromes that can cause a baby to have a cystic hygroma. Most of these conditions are rare and are often difficult to diagnose before a baby is born.

#### What will happen now?

A detailed scan will be arranged with one of the Fetal Medicine Consultants in Leighton hospital. The Fetal Medicine Consultant will discuss the options and agree the best plan for you, according to your wishes.

- As a cystic hygroma is associated with chromosome problems in the baby, you will be offered a
  test to examine the baby's chromosomes (Chorion villous sampling or amniocentesis).
- If an amniocentesis or CVS is performed, a genetic test called a microarray can be done. This test looks at the baby's genetic makeup in fine detail, but it is not possible to exclude all genetic problems before birth.
- A fetal echocardiogram (scan of the baby's heart) will also be offered since there is an association with heart abnormalities.

# **Chorionic Villus Sampling (CVS)**

This is a procedure carried out before 14 weeks of pregnancy, in which a tiny sample of tissue is removed from the placenta (afterbirth) and sent to a cytogenetic laboratory for analysis. The results of this test are usually available within 3 to 4 working days. There is a 1% (1 in 100) risk that the CVS could cause a miscarriage. If this were to happen, it would probably occur within 2 weeks of having the test. You will be given a full explanation of how CVS is performed if this test is recommended. CVS test is currently done at Liverpool Women's Hospital.

#### Amniocentesis:

The test is carried out from 15 weeks of pregnancy. This is a procedure to obtain amniotic fluid from around the baby by passing a fine needle through the abdomen and into the womb under ultrasound guidance. The test is performed at Leighton hospital.

#### If my baby's chromosomes are normal?

If your baby has normal chromosomes and the cystic hygroma disappears by 20 weeks of pregnancy with no additional physical problems identified, the outlook will probably be good. However, a cystic hygroma that disappears does not provide complete reassurance about ongoing problems, or genetic syndromes.

#### What about future pregnancies?

The risk of having further babies with a cystic hygroma is very small for the majority of mothers. If it is isolated, we usually quote a recurrence rate of the order of 1-2%.

#### **Further information and support:**

You will also have a specialist midwife who you will be able to contact for further discussion. Fetal Medicine Team – 01270 273775

#### **Antenatal Results and Choices:**

You may find this website useful for further information and support. www.arc-uk.org

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