

“increased risk of Neural Tube Defect” What does it mean?

*Information from the South Australian Maternal Serum Antenatal Screening (SAMSAS) Program,
SA Pathology at Women’s and Children’s Hospital, North Adelaide 5006*

Is there something wrong with my baby?

Everybody who receives a maternal serum screening report saying *increased risk of neural tube defect* straight away asks “is there something wrong with my baby?” At this stage the only answer that can be given is “probably not, but you should think about checking”.

90% of women who receive a report like this go on to have a normal healthy baby.

Why have I got this report?

We have performed a screening test which is designed to tell if there is a greater than expected chance (*an increased risk*) your baby *might* have a neural tube defect.

Your results indicate there is a small chance (1 in 30) that your baby *might* have a neural tube defect.

What is a neural tube defect?

Neural tube defects are rare but serious abnormalities which occur in the early development of about 1 in 500 babies. It is not known what causes them.

The two most common types are **anencephaly** and **spina bifida**.

In anencephaly there is an abnormal development of the baby’s brain and skull. Babies with anencephaly usually die soon after birth.

In spina bifida the baby’s spine does not form properly. The degree to which a baby could be affected by spina bifida depends upon how big the abnormality is, and where it occurs on the baby’s back. Babies with severe spina bifida may have paralysis of the legs, lack of bladder and bowel control, and curvature of the spine. Hydrocephalus (too much fluid around the brain) can also occur.

What does “increased risk” mean?

A maternal serum screening report saying *increased risk of neural tube defect* is only a *guide* saying that your baby *might* have a neural tube defect. It does *not* mean that your baby *definitely* has a neural tube defect. **In 9 out of every 10 pregnancies reported as being at increased risk of neural tube defect, the baby will not have a neural tube defect.** In 1 pregnancy out of every 10 reported as being at *increased risk of neural tube defect* the baby will actually

have a neural tube defect, or some other problem. Only further testing will show whether or not your baby has a neural tube defect.

What is the further testing?

The test which follows a report saying *increased risk of neural tube defect* is an ultrasound scan. Ultrasound scanning is a way of seeing your unborn baby using sound waves.

There are no known dangers to either you or your baby from ultrasound scanning.

Your baby’s head and spine will be closely examined during the scan. If your baby’s head and spine look normal on ultrasound scan, the chances of him or her having a neural tube defect are very low.

If your baby has a neural tube defect, then the ultrasound scan will usually show it. Your doctor will then explain the abnormality to you and tell you what it means.

Could my baby have something else?

Very rarely, a baby might have another type of abnormality which will be seen on ultrasound scan. If this happens to you, your doctor will give you information about the effects this may have on the rest of your pregnancy and on the baby which may be born.

Must I have further testing?

No, you do not have to. It is your choice. Discuss this with the doctor looking after your pregnancy, or contact the South Australian Maternal Serum Antenatal Screening Program on (08) 8161 7285, which will be able to refer you to counselling and support services.

What happens if my baby is shown to have a neural tube defect?

If your unborn baby is shown to have a neural tube defect, your doctor will give you information about the likely effects this will have on the rest of your pregnancy and on the baby which may be born. You should ask advice about what medical problems your baby might have, and what support services are available to you and your family.

You will then have to decide whether to continue your pregnancy or to end it early.

Where can I get more information?

More information about antenatal screening, and about what an *increased risk* result means, can be obtained from

the doctor or midwife who is looking after you during your pregnancy,

or

the SAMSAS Program
telephone (08) 8161 7285
email samsas.program@health.sa.gov.au
website www.wch.sa.gov.au/samsas.html

More information about spina bifida is available from

the Spina Bifida and Hydrocephalus Association of South Australia Inc., *telephone* (08) 8443 5200 and their *website* www.spinabifida.asn.au

or

the Spina Bifida Association of Tasmania Inc., *telephone* (03) 6223 4537

*The figures quoted here are from the South Australian Maternal Serum Antenatal Screening (SAMSAS) Program, SA Pathology, operating at the Women's & Children's Hospital, Adelaide, South Australia. They do not apply to other maternal serum testing centres.
(Revised Aug 2009)*