



Liverpool Supraregional Craniofacial Team

Genetics of Scaphocephaly (Sagittal Synostosis)

Information for parents

Introduction

The skull is made from different plates of bone which are separated by joints called sutures. These sutures allow the bones of the skull to overlap slightly so that the baby's head can pass through the birth canal during delivery. The sutures also allow for the brain to grow rapidly during the first two years of life. If one or more of the sutures fuse too early this is called craniosynostosis. Depending on which suture is affected, there will be a different head shape resulting from the craniosynostosis.

Scaphocephaly is the name given to the shape of the skull that occurs when the sagittal suture (the joint on the skull which runs from the front to the back of the skull) fuses too early.

Scaphocephaly is only rarely syndromic (part of a wider condition), more commonly it is non-syndromic. If there is no one else in the family with an unusual head shape, and if your child has no other medical problems or unusual features and has no problems with their development or growth, then we would advise this was non-syndromic scaphocephaly.

What is the cause of my child's scaphocephaly?

We do not fully understand the cause of non-syndromic scaphocephaly. In the vast majority of cases there is nothing about the pregnancy which is unusual and there is nothing a mother did or didn't do during the pregnancy which has caused the craniosynostosis. It is something that can happen to anyone.

Is there a chance that other children we may have in the future could also have craniosynostosis?

Although non-syndromic scaphocephaly does not usually run in families there is a slightly increased chance that another child you have in the future may have craniosynostosis. This chance is about 2% (*Lajeunie et al*, American Journal of Medical Genetics, 1996; 62(3):282-5) (2 chances in 100). This means that there would be a 98% chance (98 chances in 100) that any child you had in the future would not have craniosynostosis.

There are no specific tests which would be offered during a future pregnancy and non-syndromic craniosynostosis is not usually detected on a 20 week anomaly scan. However, a scan later on in pregnancy may be able to check for signs of craniosynostosis. If a baby is affected, it may help doctors to decide on the best method of delivering the baby.

What is the chance of my child having a baby affected by craniosynostosis?

We currently suggest that there would be a low (but not zero) chance of them having a child with craniosynostosis themselves. Health professionals are likely to have a greater understanding of the causes of scaphocephaly in the future. We would recommend a geneticist is contacted for information.

For further information please contact

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This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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